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Culture Change and Quality of Life in Elderly Persons Living in Long Term Care

Carol S. Jones
University of North Florida

CULTURE CHANGE AND QUALITY OF LIFE IN ELDERLY PERSONS LIVING IN LONG TERM CARE

by

Carol S. Jones

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CERTIFICATE OF APPROVAL

This project of Carol S. Jones is approved: DATE

Signature Deleted

Margaret A. Holder 10/28/10

Signature Deleted

Sharon Wilburn 10/28/10

Signature Deleted

Marcia Lyles 10/28/10

Signature eleted

Lillia M. Loriz, Committee Chairperson 10-28-10

Accepted for the Department:

Signature Deleted

Lillia M. Loriz, Director, School of Nursing 10-28-10

Accepted for the College:

Signature Deleted

Pamela S. Chally, Dean, Brooks College of Health 11-4-10

Accepted for the University:

Signature Deleted

Len Roberson, Dean of the Graduate School 12/10/10

Dedication

To my husband, Vernon, who is the wind beneath my wings…

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Abstract

Quality of life in long term care (LTC) is a concern for many stakeholders. The elders who are living in LTC facilities, their families, the staff, and government and policy makers are all interested in providing quality care and quality of life to those persons living within the facility. Culture change is one way for LTC facilities to begin to give decision making to the residents, and to increase quality of life of these elders. There are different culture change models that embrace the concept of person-centered care. No matter which model is chosen, the essence of the change is moving from a medical care model to a person-centered care model.

The purpose of this project was to evaluate the effectiveness of a culture change intervention, teaching person-centered care to certified nursing assistants (CNA), on the quality of life (QOL) of alert and oriented residents living in a LTC facility. The elders, identified as alert and oriented by a score of 25 or greater on the Mini Mental State Exam (MMSE), participated in a QOL questionnaire. Two one hour in-services on person-centered care were presented to the CNAs. The QOL questionnaire was re-administered to the elder participants after three months.

The results illustrated that teaching person-centered care to CNAs showed significant improvement in the areas of dignity and security, and marginal significance in the area of individuality. This suggests the elder's increased feeling of respect from the staff, as well as an increased sense of belonging and confidence in the availability and assistance of the staff members. It also suggests the elders felt that they were known as individual persons and that their preferences were honored.

Chapter One: Introduction

The U.S. Census Bureau estimates that by 2010, 40 million Americans will be age 65 and over. This equates to 13% of the population. By the year 2030, the U.S. Census Bureau estimates there will be 71 million people over the age of 65, which is 19.6 % of the population. By 2050 that number will grow to an estimated 86.7 million, or 20.7% of the population (U.S. Census Bureau, 2004). With the rapid increase in the number of elderly persons over the next 40 years, long term care (LTC) and culture change becomes an important topic. More Americans, as they age, will need skilled nursing care in a LTC environment. Having a home-like environment in which to age will become increasingly important to the Baby Boomers.

No one has ever wanted to live in a LTC facility, however as someone ages they may need skilled nursing care. Skilled nursing care involves health care and nursing care from licensed practical nurses (LPNs) and registered nurses (RNs) to foster and maintain the resident's highest physical and mental well-being. Many people who require skilled care also need assistance with activities of daily living (ADL). Certified nursing assistants (CNAs) provide ADL care and encourage the residents to continue to do as much as they can for themselves. The nursing staff members assist the residents to be as healthy, active, and involved in the life of the facility as possible. Culture change is gaining momentum in LTC institutions as a way to transform them into more home-like environments where elders may thrive.

Stable administrative and management staffs that are champions of culture change are necessary to successful transformation. Staff employees from all departments must

be involved in the change (Crandall, White, Schuldheis, & Talerico, 2007). Consistent staffing for frontline staff is also essential for its success, in order to allow CNAs the opportunity to get to know their residents and care for them as individuals (Misiorski, 2003).

Culture change is a national movement spearheaded by individuals working with elders living in all levels of communities from assisted living facilities to LTC institutions. The goal of this movement is to transform eldercare by altering the attitudes regarding aging in the elders themselves, their caregivers and to improve governmental policy (Fagan, 2003). Fagan (2003) asserts the need for such a transformation when she claims that "in nursing homes, assisted living facilities and adult day care programs, we supply our elders with the necessities of survival, but they are too often deprived of the necessities of living" (p. 127). Long term care facilities provide excellent quality of care, but oftentimes quality of life is overlooked. Culture change is a transformational journey that aims to create vibrant communities where the frontline staff is empowered, and the residents flourish and experience an enhanced quality of life (Rahman & Schnelle, 2008; Robinson & Gallagher, 2008). Control is returned to the elders to make decisions and the frontline staff members are empowered to assist the residents in making those decisions (Brawley, 2007). Culture change involves honoring the elders' wishes on a daily basis, authorizing the frontline staff to assist the elders to make decisions about their lives and thus improve their quality of life.

Culture change in LTC was first started in 1977 with the Live Oak Regenerative Community in California (Barkan, 2003). This grassroots movement initiated the culture change of LTC facilities from an institution to a homelike environment for elders. Since

then several models of culture change have been developed throughout the United States. These models include, in addition to the Live Oak Regenerative Community, the Eden Alternative (Thomas & Johansson, 2003), the Wellspring Model (Kehoe & Van Heesch, 2003), Neighborhoods (Ragsdale & McDougall, 2008), and the Pioneer Network (Fagan, 2003; Mitty, 2005).

Person-centered care is at the heart of each of these models. Crandall, et al. (2007) described the elements of person-centered care as "personhood, knowing the person, maximizing choice and autonomy, comfort, nurturing relationships, and a supportive physical and organizational environment" (p. 47). When person-centered care is adopted, the staff member's knowledge of the resident rises to a new level. He or she discovers what activities the resident wants to do from the time they wake up to the time they go to sleep. The staff member also learns what the resident wants to eat, how and when they want to bathe, what activities they enjoy and what they want to do each day. Their relationship further develops as frontline staff members learn details about the resident's past accomplishments, career, hobbies, friends and family. The employee also uncovers the resident's current wishes and desires, and what he or she may still want to accomplish.

Facility Readiness for Change

Palatka Health Care Center (PHCC), in Palatka, Florida, is a privately owned, for-profit, 180-bed LTC facility in rural Putman County. In 2009, the facility celebrated its twentieth anniversary of providing quality care. As one of the largest employers in the county, community involvement is very important. The administrator and the director of nursing (DON) are both very innovative and have been involved in quality improvement

programs in the past, including a Medicare collaborative on the best practice for prevention of pressure ulcers, and also a research study with the University of Texas on frequency of turning residents to prevent pressure ulcers. They are currently working with the Pioneer Network on culture change.

The culture change journey for PHCC began in the fall of 2008. The facility had been asked to participate in a study with the Pioneer Network to initiate culture change. The PHCC management team had wanted to start working on culture change, but was unsure how to proceed on its own. When the Pioneer Network contacted them about participating in their study, PHCC was ready and willing to start on this journey. The Pioneer Network is an advocacy group promoting culture change in facilities across the United States: PHCC was one of forty facilities in the study. They initially sent a culture change coach to PHCC who assisted the facility to identify what was done well to support elder choice and decision making and where there was a need for change. PHCC used "The Artifacts of Culture Change Tool" (Bowman, 2006) to identify performance in key areas. This tool was developed to assist LTC facilities "collect the major concrete changes [nursing] homes have made to care and workplace practices, policies and schedules" and to identify ways they have "increased resident autonomy, and improved environment" (Bowman, 2006, p. 5).

One of the major needs identified for adjustment during this time was for the removal the nurses' station from the center of the halls on the two LTC units. This environmental change created a living room area in the center of the units with music, a computer, and a sitting area. Interestingly, rearranging the environment did not change the culture. Prior to this change the residents would sit around the nurse's station all day

with little to do unless there was an activity going on. With the nurse's station moved and the living room in the center of the unit, the residents still sat with little to do unless there was a formal activity going on. "An institutional model with only the physical renovations is like a caterpillar with wings. Physical renovations alone don't reflect transformational change. A caterpillar with wings is not yet a butterfly," (Norton as quoted in Grant & McMahon, 2008, p. 54). The physical change to the units did not transform the culture and the way the residents spent their day: it only created a living room area.

In reviewing the successes of the culture change journey and the areas that needed improvement, the management team at PHCC realized that while the environment had changed, something was still missing. A review of the literature revealed the need to change from a medical model to a person-centered model. A medical model organizes care that is task oriented and revolves around caring for sick people. Person-centered care moves from a task-oriented mindset, in which the frontline staff members work from a schedule that does not include input from the resident, to an environment that focuses on the resident and their daily choices. In a medical model, the CNAs organize the work around getting residents up, bathed and fed. On the other hand, a person-centered care model directs the CNAs to focus on what each resident wants to do that day, starting with when they want to get up, when they want to eat, and which activities they want to attend. The CNA knows specific care and comfort desires of each resident including when a resident might like to take a nap during the day, the way they like the covers arranged, and which light to leave on. The concept of person-centered care is essential to changing the culture of the units and how the frontline staff see and "know" the residents.

The idea of teaching the concept of person-centered care to the CNAs was proposed to the Administrator, DON and Medical Director by the Risk Manager. The environmental change was discussed and the lack of true change in the culture was identified. The initiation of person-centered care was proposed to change how the frontline staff think and organize their day. Transforming from a medical model into a person-centered care model was embraced and verbal approval was given to proceed with the project. A formal presentation was made about the project and approved by the Quality Assurance/ Risk Management committee.

Project

This project was a practice change project. It began with two one- hour in-services on person-centered care presented to the CNAs. The aim was to evaluate the impact of teaching CNAs person-centered care on the quality of life of the alert and oriented elders living at the facility. A Quality of Life questionnaire, "Quality of Life Scales for Nursing Home Residents" (Kane, 2003) was given to the alert and oriented residents prior to the in-service and repeated three months after the in-service.

The purpose of this project was to evaluate the effect of a person-centered culture change intervention on the quality of life of alert and oriented elders living in a LTC facility. The management staff at PHCC, where the proposed project was conducted, had been there between two to twenty years. Of the 240 employees at PHCC, 92 were members of the "Five Year Club" with five or more years of service. Staff at all levels had been involved in culture change meetings since September 2008. In addition, consistent staff assignments had been in place for many years. Staff retention and consistent assignments combined to make PHCC an ideal location to continue the culture

change journey. The next step was to transform the care delivery model from a medical model to a person-centered care model. The question that was addressed in this project was: *Does person-centered care affect the quality of life of alert and oriented elders living in a long term care facility?*

The following chapter includes a review of the literature and the strategies used to retrieve the evidence on this matter. An analysis of the studies evaluated and the evidence chosen will be identified and examined in more detail.

Chapter 2: Literature Review

This chapter contains a review of search strategies used for identification and retrieval of the research evidence relevant to the proposed project. This is followed by a review of the definitions of culture, medical-based culture, and culture change. Person-centered care is then examined in detail, followed by a review of studies on person-centered care.

Search Strategies

A systematic search of CINAHL, PubMed, and the Cochrane Library was conducted for the period October 1, 2009 through October 31, 2009 using the key words *"culture change in nursing homes"*, *"culture change in long term care"* and *"person-centered care"*. No Cochrane Reviews were returned for any of these word choices. In CINAHL word choices *"culture change and long term care"* returned 364 items, *"culture change and nursing homes"* returned 195 items, and *"person centered care"* returned 181 items. This search was further refined to include *"person-centered care and long term care"* which returned 36 items, and *"person-centered care and nursing homes"* returned 30 items. When PubMed was reviewed for *"culture change and long term care"* 145 items returned, and *"culture change and nursing homes"* returned 84 items. When the phrase *"person-centered care"* was entered in the computer there were163 items returned. This was further revised to *"person-centered care and long term care"* which returned 29 items and *"person-centered care and nursing homes"* which returned 33 items. After accounting for duplication of resources across databases, a total of 10 studies, and 37 articles were reviewed.

Culture

Culture is defined by the Merriam-Webster Dictionary (2010) as "the integrated pattern of human knowledge, belief, and behavior that depends upon the capacity for learning and transmitting knowledge to succeeding generations, the characteristic features of everyday existence (as diversions or a way of life) shared by people in a place or time." Misiorski (2003) defined culture as a group of customs and ways of doing things that a group living together passes down from generation to generation. Dixon (2002) offers a definition of culture specific to LTC as shared values, assumptions, attitudes, feelings and beliefs learned over time about how work is accomplished in a nursing home. According to him, a part of this culture is the staff's attitudes and beliefs, whether articulated or not, that drive commitment and action (Dixon, 2002).

Medical Model

The current culture in LTC is a medical model. In the 1960's Medicare and Medicaid were passed and from that time forward LTC facilities were designed like hospitals. Management and care of the LTC residents included prescribed routines related to disease and physical care until death. In 1987 the United States Congress passed the Omnibus Budget Reconciliation Act (OBRA '87) which required all LTC facilities to promote the maintenance or enhancement of quality care for each of their residents. This was accomplished by formulating a written care plan assessing each resident's care needs, which was then implemented to attain their highest level of well-being (Robinson & Gallagher, 2008).

In 1986, the Institute of Medicine (IOM) issued a report entitled *Improving the Quality of Care in Nursing Homes* that sought to improve care. While this report did

successfully improve care, the result was an institutional, medical model (Flesner, 2009). A medical model views people by their illness and disability, and this has formed the institutional view of people in a LTC facility (Barkan, 2003). Rather than focus on quality of life, a medical model places the most emphasis on quality of care. The time for medications, treatments, and activities are scheduled around traditional eight-hour shift schedules. When to sleep, eat and bathe is dictated by a schedule, instead of a personal preference (Kransnausky, 2004). Medical model facilities direct most of their attention to maintaining an efficient operation, unfortunately at the expense of the needs and wants of their residents. The focus is to treat the resident's weakness, not to develop their strengths (Holzer, 2007).

Classic attributes of a medical model include staff providing care based on a medical diagnosis, schedules and treatment, each designed by the institution staff without regard to resident choice. Work is task-oriented and the staff members rotate assignments frequently. The environment is hospital-like, decision making is centralized, and activities are available only when the activity staff is working. Loneliness and isolation are often seen in the residents living within this sort of model (Misiorski, 2003).

Culture Change

Culture change is not an isolated event. It is a journey that continues through time and keeps evolving: there is no blueprint to culture change. Each nursing home makes its own decisions to modify policies and procedures, manage staff, make environmental changes to be more home-like, and to organize care for the elderly living in their facility (Norton, 2003).

Culture change is approached in different ways by different facilities. The key to culture change is offering the residents more choices, such as when they get up and when they go to sleep, or even more choices in dining, by creating "fine dining" for all in the dining room. The elders choose what they want to do and when they want to do it, and in so choosing increase the quality of their lives.

Part of culture change is the "flattening of the hierarchy", changing decision making from a top down fashion to decisions made by the residents and the frontline staff (Ragsdale & McDougall, 2008). Instead of the administrator and management staff making all the decisions, the residents and the CNAs are all involved in the decision making affecting the facility. No matter what model of culture change is chosen, altering the decision making process is essential to transforming the facility. There are different models that best exemplify culture change including the Regenerative Community (Barkan, 2003), the Eden Alternative (Thomas & Johansson, 2003), the Wellspring Model (Kehoe & Van Heesch, 2003), the Neighborhood model (Robinson & Gallagher, 2008), and the Pioneer Network (Fagan 2003).

In 1977, Dr. Barry Barkan initiated the Live Oak Regenerative Community. Their entire culture is built around the idea of community with the elder at its center. In this community, regeneration is understood as a life long journey and process. It is enhanced by listening to people's needs and acting on those needs (Barkan, 2003). This community is based on Erikson's developmental stages theory, which states that aging is another stage of life and a person still develops as they become older (Mitty, 2005). The community downplays illness and builds on resident strengths, despite deteriorating health (Holzer, 2007).

The Eden Alternative was started by Dr. William Thomas, who believed that elders can thrive in an environment that prevents the three "plagues" of nursing homes: loneliness, helplessness and boredom. Dr. Thomas identified two fundamental ideas. The first is that decisions need to be with the elders or by the caregivers closest to them. The second is that the staff will treat the elders the way that management treats the staff. If the management staff is concerned and care about their staff and each staff member's life, the staff in turn will treat the residents with care and concern. Children, plants and animals help the elders to thrive by restoring relationships and spontaneity to daily life (Thomas & Johansson, 2003; Rantz & Flesner, 2004; Fagan, 2003).

The Wellspring Model is a confederation of not-for profit freestanding nursing homes in Eastern Wisconsin who joined together to create a better living place for the residents and a better work environment for the employees. Advanced Practice Nurses are employed as consultants to translate research-based evidence to the practice of the clinical staff, in order to transform and improve the daily care of the residents. The fundamental definitions of quality of care are developed by top management, but the decision-making is best done by frontline staff closest to the resident (Kehoe & Van Heesch, 2003; Robinson & Gallagher, 2008; Holzner, 2007). One study of this system revealed improved quality outcomes, decreased staff turnover and improved staff retention (Rahman & Schnelle, 2008).

The Neighborhood Model transforms large communal spaces into living areas for 8-20 residents in a home-like environment, cared for by consistent staff who are cross-trained to perform a variety of jobs. Each neighborhood has its own kitchen, laundry, living room and dining room. Resident decision making is the center of the

Neighborhood Model (Robinson & Gallagher, 2008). Daily chores and decisions about activities are decided by the residents and the CNAs caring for them.

The Pioneer Network is an organization of culture change advocates involved in LTC. They believe that to have meaningful lives the elderly need to have "dignity, choice and self-determination" (Fagan 2003, p. 126). Principles of the Pioneer Network include returning decision making to the residents, empowering the caregiver at the bedside, creating a home-like environment and continuing the resident's familiar routines such as in getting up, going to bed, when to eat and bathe (Mitty, 2005). The goal is for residents to live in dignity and comfort and maintain control of their lives (Krasnausky, 2004).

Person-Centered Care

Throughout the literature on all these models is the concept of person-centered care. At the heart of person-centered care is the relationship between the elder and the caregiving staff. The resident is honored and not lost in the daily tasks of caring for the dependent person. The importance of the care is on the quality of life of the elder being cared for (Crandall et al., 2007). The main attribute to this type of culture is that the staff is invested in a relationship with the elder based on each resident's individual needs. The residents' schedule is designed by the elder and the caregiver. Consistent staff, with the staff's personal knowledge of the elder, is brought into the relationship. Decision making is with the residents or the frontline staff who care for them. The environment is home-like, spontaneous activities are available around the clock, and there is a sense of belonging (Misiorski, 2003; Robinson & Gallagher, 2008). Person-centered care is part of the facility's mission, not just a project and the systems are in place to support and

sustain this change through policy and procedures, job descriptions and education. There is involvement and commitment at all levels of the facility (Crandall, et al, 2007). Person-centered care also involves the resident's family, friends and social network (Talerico, O'Brien, & Swafford, 2003).

The cornerstone of person-centered care is relationships. The person is put before the task. Self determination is a right and risk taking is part of life, even in a LTC facility. More than just physical care, the elder's spirit and mind are nurtured in an environment that promotes growth and development throughout the life span (Flesner, 2009). The idea that caregiving is the basis of relationships is expressed in the following way:

> Caregiving is not one person doing a favor for another or giving to another who is simply a recipient. Rather, it is a relationship in which there is a give and take and a bond that is made, person to person. Moreover, it is a living and growing bond which both participants shape and nourish. (Williams, 2003, p. 2)

Beyond the relationship between residents and frontline staff in person-centered care is the relationship between frontline staff and supervision. CNAs need to know that they are appreciated, understood, and cared about. They need to feel that they are recognized as a person with a family, hopes and dreams and appreciated for the gifts they bring to the work situation (Williams, 2003).

Review of Studies

According to the literature there are benefits to the facility practicing person-centered care. In a case study by Rantz and Flesner (2004), positive clinical outcomes of person-centered care included lower state and national averages regarding the loss of

ability in basic ADL's, pressure ulcers, pain, and physical restraints. Resident occupancy rates were higher (98.4%) and staff turnover was decreased. Benefits for residents included respect for life-long patterns, community connections were maintained and individualized requests were honored. Close relationships with staff was encouraged, the elders continued to contribute to society, and elder satisfaction with their living arrangements was increased. There was reduction in weight loss, improved eating habits and a reduction in sleeping medication usage. Other benefits included reduction in use of catheters and briefs, reduction in psychotropic drug use, reduction in restraint usage, and reduction in use of anti-anxiety medications. The elders reported improved control over their schedule (Rantz & Flesner, 2004). Staff benefits included open communication, with decentralized decision making, and increased support for employees and their personal lives. The management team encouraged staff to develop relationships with the residents. There was a consistent team assignment with increased job satisfaction. There was autonomy and empowerment of the frontline staff with greater enjoyment of work. Teamwork became a reality, with closer relationships with the residents. The CNAs knowledge of resident routines increased and there was reduced turnover. Communication was more open at all levels (Rantz & Flesner, 2004).

Similar results were reported at Providence Mount St. Vincent in Seattle with a reported decreased incidence of decline in ADL's and weight loss. There were a decreased number of pressure ulcers. There was improved employee satisfaction, and decreased turnover (Zigmond, 2009; Elliott, 2009). In a study on residents with dementia, Rasin and Kautz (2007) found that staff that who "knew" the residents provided higher quality of care by knowing their life history, anticipating needs and

knowing when something was wrong with the resident. Staff in turn felt more job satisfaction and were more attached to the resident.

In a study by Ragsdale and McDougall (2008), two traditional nursing homes were converted into "Green Houses" and were compared to traditional nursing homes. A Green House is a home with 8-20 residents, a living room, kitchen, and laundry room in each house. Staff is cross trained to do multiple chores. Decision making is done on a daily basis with the residents deciding what they want to do each day. In this study one hundred and forty residents from a traditional nursing home moved to four Green Houses (based on the Eden Alternative). The Minimum Data Set (MDS) was used to capture resident quality indicators. Staff outcomes including absenteeism, turnover and work related injuries were measured. The study showed small houses increased quality of care indicators, satisfaction of residents and staff, and decreased turnover of staff.

Weiner, Barsade, and Burack (2009) conducted a longitudinal study involving seven culture change communities and six control communities. Elders, their families and staff members in 13 communities were studied and measured over three time periods. The researchers gathered information through surveys, QOL and behavioral measures of residents, turnover of staff, and empowerment of the CNA. The study showed increased QOL and satisfaction among elders, families and staff. Over the length of the study, however, all of the communities started to implement some level of culture change, and may have skewed the results.

Bond and Fiedler (1999) conducted a study that looked at change in organizational culture as measured on three survey scales. One unit had architectural changes to make it more "home-like". One unit had a goal setting/behavioral modeling

approach and the third unit was the control unit with no changes made. Three scales measured results on each of the three units. An "Encouragement Scale" measured the degree to which staff encouraged residents to be independent. A second scale described the neighborhood's organizational culture. The third scale measured "Team Relations". Each scale was collected at baseline and at six months. Change in environment was statistically significant. The study did not elaborate on the characteristics of a behavioral/role model.

Robinson and Rosher (2006) performed a longitudinal study implementing the four phases of the Eden Alternative. Change was measured using pre- and post- surveys of the elders living in a LTC facility, their families, and the staff. There was statistically significant improvement in family and resident satisfaction. Despite all the changes no real difference was reported in staff satisfaction. This is attributed to turnover in administrative staff who did not champion culture change and illustrated the importance of a stable management staff who support and advocate for transformational change.

Caspar, O'Rourke, and Gutman (2009) implemented a pre- and post- survey using a convenience sample of RNs, LPNs, and care aides from 54 LTC facilities in British Columbia. Forty-eight percent of facilities had implemented a culture change model. The study showed that the traditional hierarchal medical model remained evident in LTC. The frontline care staff furthest from the resident had the most power to make decisions (RNs). The study also showed that to successfully initiate culture change the care staff needs to be empowered to make these decisions.

Tellis-Nayak (2007) conducted a study using surveys on perceptions of culture change by staff and families using surveys. The staff was given an 18 item survey on

four dimensions of quality: training, supervision, management by administrator and DON, and work environment. The families of the residents completed a 24 item survey looking at quality of care, quality of life and quality of service. State inspection survey results from each of the 156 facilities were also analyzed. Data showed that managers played an important role in CNA loyalty, commitment and satisfaction. This in turn appeared to result in the positive well-being of the residents. If person-centered care is to be initiated, the findings in this study help to identify what is important to the CNAs, which may result in higher quality of care to residents.

A qualitative study by Clarke, Hanson, and Ross (2003) involved eight patients and their families and six support workers. The support workers helped to compile life stories in a scrapbook written by family members or care aides with pictures supplied by the family. Focus groups were held at the beginning and at the end of the study. This study showed that the use of biographical data helped to improve person-centered care. The staff saw who the person really was and had been, not as just an elderly sick person. The staff found that they had better relationships with the families because of the story telling.

In reviewing the current research, the overall result of changing the culture of a LTC facility to person-centered care is an improvement in the overall care of the facility. Quality of care improved, quality of life was enhanced, staff retention increased, resident, family, and staff satisfaction increased, and occupancy rates increased all positive outcomes of culture change within a facility.

Evidence Chosen

The following evidence-based interventions and tools were used in this project:

1. Teaching person-centered care to CNAs in an in-service program improves resident satisfaction.
2. Use of a "Resident Sensitivity Exercise" to increase awareness of the CNAs regarding how it feels to be an elder living in an institution (e.g. LTC facility).
3. Use of a "Wants and Desires" form to increase the CNAs knowledge of the resident and the ability to perform person-centered care.

Discussion of these tools and interventions follows.

Research in culture change is still in its infancy. Most reported research involves case studies, surveys and small samples. Little research has been done on person-centered care. A quasi-experimental study (Grosch, Medvene, & Wolcott, 2008) was conducted teaching nursing assistant students person-centered care as part of their core curriculum with a control group that was not instructed on this topic. At the end of the class both groups provided care to a scripted elder and were videotaped. The researchers had two resident volunteers who were given a script to follow. The student nursing assistant was supposed to wake up the resident, help him put on glasses (that were smeared) and to assist the resident to walk with his walker to the dining room. While the resident was walking he was supposed to rub his hip like he was in pain. The resident reported greater satisfaction from the nursing assistants who were instructed in person-centered care. This study is the basis of evidence for the planned intervention on person-centered care.

Two case studies that utilized person-centered care as the concept behind culture change interventions were also reviewed. In a case study by Elliott (2009) at Providence Mount St. Vincent, in Seattle, the team used a "Resident Sensitivity Exercise" form in a

leadership team meeting to increase sensitivity of the staff (see Appendix B). The premise of the exercise was for staff to answer the questions about personal preference regarding wake up time, breakfast routines, TV preferred, and bedtime rituals. The leader of the meeting had the staff share their preferences then asked the group to consider a life based on someone else's schedule and preferences.

The other component of the intervention is a "Wants and Desires" form from a case study by Rantz and Flesner (2004) which assisted CNAs to learn about the resident's wants and desires (see Appendix C). The form contains daily routines including favorite drinks, foods, daily morning routine, evening routine, activity of daily living (ADL) routine, personal care preferences, assistance needed, unique hygiene needs, bath routine, and even improvements the resident desires and what he or she want to accomplish.

Culture change is different in each LTC facility, based on the uniqueness of each facility. Resident choice and honoring the wishes of elders is evident in each model and the wishes of the elders are honored. Environmental changes can be made, wake up times, bath times, and dining services can all be altered. Unless the care model is changed from an institutional, medical model to a person-centered care model true culture change cannot occur. In reviewing the literature and research studies it is evident that an intervention that teaches person-centered care improves resident satisfaction and quality of life of elders living in a LTC facility.

Chapter 3: Methodology

This chapter includes a description of the design, setting and sample for the project and the methods and procedures for the study. A discussion of the feasibility and data analysis plan and protection of human subjects is also presented.

Study Design

This project was the implementation of an evidence-based practice change. The purpose of this project was to observe the effect of a person-centered culture change intervention on the QOL of alert and oriented elders living in a LTC facility. This study was a one group before and after cohort design, with a baseline QOL evaluation of the study residents obtained prior to the start of the study and a reevaluation three months after the intervention. Two in-services teaching person-centered care was provided to CNAs caring for elderly residents living in a LTC facility.

Sample

Criteria for inclusion in the study were residents who were alert and oriented, living on two 60-bed long term care units, and who had Mini Mental State Exam (MMSE) scores of 25 or greater at the time of the intervention. Any residents who did not meet the inclusion criteria were not invited to participate in the study.

Setting

The study was conducted at Palatka Health Care Center in Palatka, Florida on the "A Wing" and "B Wing" units. Each unit had 60 beds for LTC residents. The two units

are almost identical with the majority of the rooms being double occupancy. There are six private rooms on "A Wing" and four private rooms on "B Wing".

Methods

Participants were recruited based on a score of 25 or greater on the MMSE. MMSE are completed quarterly at PHCC by the social worker and are on each chart. Reliability and validity of the MMSE has been tested extensively. A score of 24 and lower shows dementia (Chiriboga, McHugh & Sweeney, 2004; Folstein, M., Folstein S., & McHugh, 1975; Gagnon, et al., 1990; Mitrushina & Satz, 1991; O'Connor, et al., 1989; Tierney, Szalai, Dunn, Geslani & McDowell, 2000). Conversely a score of 25 or greater would show intact cognition.

Quality of Life Tool

The overall QOL of the elders involved in this project was measured using the "Quality of Life Scales for Nursing Home Residents" (Kane, 2003). This QOL tool was developed to specifically measure QOL in persons living in LTC facilities. This tool has 11 QOL domains that evaluate nursing home life. These domains are comfort, functional competence, autonomy, dignity, privacy, individuality, meaningful activity, relationships, enjoyment, security and spiritual well-being.

According to Kane, Kling, Bershadsky, R.L. Kane, Giles, Degenholtz and Cutler (2003) comfort and security are the basic foundations to quality of life. The comfort domain includes physical comfort: free from pain and other physical discomforts such as being too hot or too cold, in a position for too long, or having trouble sleeping (Cutler & Kane, 2004). The security domain addresses the resident's perception of his or her overall safety, security and order. This domain addresses the elder's feelings of personal

safety, their ability to move around freely, their belief that their possessions are safe, and that the staff has good intentions. The elder knows and understands the rules, routines, and expectations of the facility (Kane, 2003; Kane, et al., 2003; Cutler & Kane, 2004).

There are four domains that are related to the social sphere: relationships, meaningful activities, functional competence, and enjoyment. Relationships include engaging in meaningful relationships within and outside of the facility. These relationships can include other residents, staff, family, and friends. Kane (2003) describes meaningful activities as "residents engage in discretionary behavior that results in self-affirming competence or active pleasure in the doing or watching of the activity." Functional competence addresses the idea of the resident being as independent as they wish to be within their physical and cognitive ability (Kane et al., 2003; Kane, 2003). The enjoyment domain refers to enjoyment of food and mealtimes (Kane et al., 2003; Kane, 2003).

The idea of self worth and individual agency is captured on the QOL tool with four domains: individuality, autonomy, privacy, and dignity. The individuality domain measures the residents' ability to express their preferences and engage in their past and current interests while maintaining a sense of self and their own identity (Kane et al., 2003; Kane, 2003). Autonomy refers to the residents' ability to be self-directing and to make choices about their care and lives (Kane et al., 2003; Kane, 2003). Privacy includes being able to have bodily privacy, alone time, a private place to visit with others, and to be able to keep their personal information private (Kane et al., 2003; Kane, 2003). Dignity refers to the resident feeling that their dignity is respected and is intact. They do not feel belittled, devalued or humiliated (Kane et al., 2003; Kane, 2003).

The final domain is spiritual well-being which addresses the residents' need for prayer, religion, meditation, and spirituality (Kane et al., 2003; Kane, 2003).

A summary scale is also provided as a comparison to the individual domains.

The Quality of Life Scale for Nursing Home Residents (Kane, 2003) was administered to the study participants prior to the culture change intervention and again three months after the intervention (see Appendix D). Reliability and validity have been evaluated in several studies that have used this tool (Kane et al., 2003; Kane et al., 2004). A four-point likert scale (*often, sometimes, rarely or never*) was used to quantify the answers. According to the author, the tool could be administered in 20 to 45 minutes. Administration of the tool could be divided into two sessions if the resident became tired (Kane, 2003). Permission to use this QOL was given by the author, Dr. Rosalie Kane (see Appendix E).

Confirmatory Factor Analysis (CFA) was done on the Quality of Life Scale for Nursing Home Residents using all 54 items: the author was able to confirm the 11 domains, showing that they are related, but independent. The dignity and security domains, as well as the autonomy and privacy domains, were the most inter-correlated (Kane, 2004). Kane (2004) reported Cronbach's alpha coefficient, which measures internal consistency, or how closely related a set of items are as a group, was calculated for the Quality of Life Scale for Nursing Home Residents. Ideally, alpha coefficients should be above .7. The 11 domains ranged from .64 to .83, except in the domain of individuality, for which the Cronbach's alpha was .57.

Validity of the domain scales was calculated by regression analysis. Kane (2004) "regressed the summary measures for each domain against each domain scale. When all

respondents were considered, the corresponding summary measures were significantly correlated with the domain scale every time" (p. 3.26). Another regression analysis was completed on "the domain scores against the ultimate summary measure, the respondent's rating of life as a whole. Four domains were significantly related to life as a whole (comfort, meaningful activity, individuality, and spiritual well-being)" (Kane, 2004, p. 3.27). Validity was thus tested in two different regressions showing acceptable validity for this tool.

Sample size needed for a power of 80% and alpha of 5% would be 12 to 17, and a power of 90% and an alpha of 1% would be 14 to 32 (Kane et al., 2003; Kane et al., 2004). The planned sample included at least 20 residents.

The change model chosen for this study was developed by the Rhode Island Quality Improvement Organization (QIO) called the Holistic Approach to Transformational Change (HATCh) (see Appendix F). This model assists LTC facilities move from an institutional culture (medical model) to a person-centered care culture (Quality Partners of Rhode Island, 2006). At the center of the model is a heart that represents the resident who is the center of care. There are three intertwined circles surrounding the heart. These domains are critical in transforming the life and care of the residents. The first circle is "Workplace Practices", which includes activities, procedures, work designs, systems and individuals. This domain is critical because it is linked to good care, good jobs and LTC facility staff stability. The "Environment" is the next domain, where the facility is truly transformed into a home-like environment. The third domain is "Care Practices", which includes medical care, clinical care and systems, quality improvement, activities, rituals, celebrations, and the dying, waking and dining

experiences. These three domains are nested in another circle "Leadership". This represents leadership at all levels of the facility. Empowerment of CNAs occurs in this domain and this domain was the focus of this study. A fifth domain, "Family and Community", encircles "Leadership". This is essential to encourage relationships with families and the community. The final circle is "Government and Regulation", which offers a partnership between regulatory/government agencies and the LTC facility to aid and complete the transformation. (Quality Partners of Rhode Island, 2006)

The culture change intervention, given by the principal investigator, was two one-hour in-services for all CNAs employed at the time the study was initiated. A discussion of how the CNAs organize their day to illustrate the medical model and how they are task oriented was included in the in-service. This was followed with the "Resident Sensitivity Exercise", which heightened the CNAs awareness of how it would feel to live in an institution and be told when to get up, bathe, what to eat and what activities to attend. A PowerPoint presentation contrasted a medical model of care with person-centered care. The "Wants and Desires" form was introduced while at the in-service and each CNA got to practice filling one out on a resident of their own choosing. At the end of the in-services the "Wants and Desires" form was placed in a separate notebook for each shift to add to the information. There are three different subsets of CNAs: primary CNAs, who give direct care to the resident; bath CNAs, who give the resident a "spa-type" shower or bath; and activity CNAs who provide activities for the residents. The goal in completing the form was for the activity CNAs to assist with information about the life history, the bath CNAs to fill out personal preferences about bathing, and the primary CNAs to complete favorite foods and beverages, and morning or evening care preferences. The

night shift (11 P.M. – 7 A.M.) included information about the resident's nighttime patterns. See Appendix G for Person-centered Care teaching plans.

The in-service project consisted of three parts:

1. During the in-services the task-oriented, medical model of care was contrasted with person-centered care. The "Resident Sensitivity Exercise" (see Appendix B) was used to help the CNAs consider their preferences for getting up and going to bed, and what activities they enjoy. They compared their preferences with being institutionalized and being told they will get up at 6:00 A.M. and have breakfast at 7:15 A.M., even if they like to sleep until 8:30 A.M. This helped them to put themselves in the residents' place and be more sensitive to the residents' preferences.
2. A worksheet on resident "Wants and Desires" (see Appendix C) was introduced to the CNAs to use in their documentation books. On this form the CNAs write information about the resident's Life History, Habits, and Daily Routine which includes favorite drinks and preferred foods. There is a section for Cycle of Daily Events including morning routine, evening routine and activities of daily living (ADL) routine. An area for bath routine, unique hygiene needs, and any area in which the resident needs assistance is also on the form. All of the CNAs added to the form on each shift and got to know and understand each resident's patterns and choices. Many of the CNAs already knew this information and could easily complete the form. The value of the form was for use when another CNA is caring for the resident, so the same routine can be followed if the primary CNA was not working that day.

3. Quality of life was measured in alert and oriented resident prior to the intervention and again three months after the intervention. This measurement assessed the effectiveness of the person-centered care in-service and if this has changed the resident's quality of life.

The time required for the completion of this study included the following time line:

1) Compiling the MMSE scores of all the residents on the two units and selection of the study population which was done in one day by the principle investigator.
2) Obtaining permission and administering the QOL tool to the study population took two weeks by the principle investigator.
3) Implementing the in-servicing of the CNAs. The in-service was offered at 7:15 A.M., 2:00 P.M., and 3:15 P.M. on four different weekdays and two weekend days within a two week period.
4) After the completion of the final in-service a three month period occurred.
5) At the end of three months the QOL tool was administered to the study population by the principle investigator again taking two weeks.

Table 1 *Project Timetable*

Date	**Time**	**Activity**
1st of month	Day 1	Gathered MMSE Scores and choose study population.
15th of month	Day 2 to 15	Obtained permission and administered the QOL tool to the study population.
30th of month	Day 16- 31	Implemented the in-servicing for the C.N.A.'s.
3 months later	Day 120	QOL tool administered to the study population again

Feasibility

Permission for conducting the study was obtained through the Quality Assurance/ Risk Management Committee at Palatka Health Care Center (PHCC) and the University of North Florida (UNF) Institutional Review Board (IRB), IRB #10-028. The cost of conducting this study was limited to the cost of the paper and printing of the seven page QOL tool twice for the study participants, the Resident Sensitivity Exercise and the Wants and Desires form for use in the in-service for 90 CNAs. Buttons were made at the facility with butterflies on them and the words "We Transform Care". Each CNA received a button, a pocket-size notebook with a butterfly on it and a pen at the in-service. The cost of copies of the Wants and Desires form for use on the units in the ADL books was paid for by the facility and ongoing as approved by the Director of Nursing (DON).

Data Evaluation

Evaluation of the data obtained from the QOL was done using SPSS software and the assistance of a statistician. Statistical significance was set at $p \leq 0.05$. Paired *t*-tests and analysis of covariance (ANCOVA) was used to evaluate the interval data. Descriptive statistics were used to identify descriptive information such as age, race, and gender.

Protection of Human Subjects

Protection of the elders participating in this study was of paramount importance. Prior to the initiation of the study approval by the PHCC Quality Assurance/ Risk Management Committee and the UNF IRB approval was obtained. All institutional, state and federal regulations with respect to use of human subjects were adhered to. There

were no foreseeable risks to the residents involved in this project. Written informed consent was obtained from each participant prior to participation in the study. Each participant was assigned a study number. There was a master list with resident name, room number, study number, and MMSE score kept in a separate, locked file that only the primary investigator had access to. All data collected during this study was stored on a secure electronic server at the University of North Florida. Access to the data was password protected and available only to the primary investigator. Any documents that would link a participant with their study number were destroyed as soon as possible after the study ended.

Chapter 4: Results

This chapter includes a discussion of the results found in response to the question posed in the beginning of this project: "Does person-centered care affect the quality of life of alert and oriented elders living in a long term care facility?" An interpretation of the results and confounding factors will also be discussed.

Sample

The sample consisted originally of 31 alert and oriented elders. One elder was unable to complete the tool, even after multiple attempts. One elder was discharged home with family after completing the first interview. The final sample consisted of 29 elders who completed both sets of QOL interviews. A sample size needed for a power of 80% and alpha of 5% would be 7 to 17 participants, and a power of 90% and an alpha of 1% would be 14 to 32 participants (Kane, et al., 2003; Kane, et al., 2004). Therefore, this project had good power related to the sample size. To create a score for each domain 75% of the questions had to be answered. When that condition was met an average of the questions answered was computed and used for the unanswered questions. If 75% of the questions in a domain were not answered the domain score could not be calculated (Kane, 2003).

The sample consisted of 24 women and 5 men, 25 of which were Caucasians and 4 African-Americans. The age of the participants ranged from 63 years old to 96 years old, with an average of 81 years old.

Quality of Life Tool

Table 1 contains average domain scores for each of the eleven domains. One can compare the scores for each domain at times one and two. For example, there were 28 respondents for DIG1 (Dignity at time 1) and DIG2 (Dignity at time 2). This domain consists of k = 5 questions on a likert scale of 1 to 4; hence the maximum score for this domain is 20. Using this benchmark one can see that an average score on DIG1 of 18.679 (Standard deviation = 1.887) is high. Normalizing the scores (dividing the domain score by the number of questions within the domain) makes interpretation of the scores easier and also aids in making comparisons between domains. For example, after normalizing, the average for DIG1 is 3.73 (Standard deviation = 0.377) and the average score for DIG2 is 3.84 (Standard deviation = 0.347). Observe that when considering the scale (1 to 4), the averages are high at both times. The standard deviations indicate that there is only modest variability within this domain. The observed difference (Table 1) in pre versus post interview is only $3.84 - 3.73 = 0.11$ on the normalized scale (compared to $19.207 - 18.679 = 0.5286$ on the raw scale). We will see in the next paragraph, however, that this difference is statistically significant. For an overall picture of the normalized scores for each of the domains, see Figure 1.

Using SPSS, a paired *t*-test was conducted to compare the average scores from the first QOL interview to the second QOL interview for all eleven domains (see Table 2). These tests were performed on the raw (un-normalized) scores (but the statistical tests would have the same p-values using the normalized scores). There were three domains that were statistically significant at the 5% level of significance. The domains of dignity (t (27) = 2.152, p = 0.041, d = 1.29, 95% CI 0.02 to 1.03) and a mean of 0.586, security (t

(27)= 2.44, p = 0.021 , d = 1.64, 95% CI 0.12 to 1.39) and a mean of 0.757. Both showed a significant increase in QOL from the first interview to the second interview. For example, with a 95% confidence the dignity domain score increased between 0.02 and 1.03 (see Table 2), indicating that the mean increase could be as large as 1.03 (note that this is only an increase of 1.03/5 = 0.20 on the normalized scale). Individuality showed marginal significance (t(25) = 1.99, p = 0.058, d = 3.58, 95% CI [-0.48 to 2.84]).

Table 2 *Means and Standard deviations of domain scores and normalized domain scores for Interview 1 and 2*

		n = # of respondents per domain	k = # items comprising domain	Mean domain score	Std Deviation of domain score	Mean normalized domain score (mean/k)	Std Dev of normalized domain Score
Pair 1	CMF1	28	6	17.518	3.5316	2.92	.5834
Pair 1	CMF2	28	6	17.393	3.5085	2.89	.5833
Pair 2	FC1	28	5	16.214	4.1665	3.24	.8447
Pair 2	FC2	28	5	16.871	3.7839	3.37	.7510
Pair 3	PRI1	26	5	17.792	3.2202	3.56	.3543
Pair 3	PRI2	26	5	18.431	1.7733	3.68	.6438
Pair 4	DIG1	28	5	18.679	1.8867	3.73	.3469
Pair 4	DIG2	28	5	19.207	1.7346	3.84	.3773
Pair 5	MA1	28	6	18.136	3.8786	3.03	.6116
Pair 5	MA2	28	6	18.386	3.6355	3.06	.6298
Pair 6	REL1	28	5	17.679	2.4803	3.53	.5303
Pair 6	REL2	28	5	17.850	2.6514	3.57	.5054
Pair 7	AUT1	28	4	14.052	2.2728	3.63	.4217
Pair 7	AUT2	28	4	14.438	1.6703	3.61	.5739
Pair 8	ENJ1	28	3	9.279	2.5868	3.09	.8610
Pair 8	ENJ2	28	3	9.786	2.5871	3.26	.8668

Pair 9	SWB1	28	4	13.207	2.9062	3.30	.5398
Pair 9	SWB2	28	4	13.652	2.1531	3.41	.7293
Pair 10	SEC1	28	5	16.757	1.7447	3.35	.2491
Pair 10	SEC2	28	5	17.514	1.2642	3.50	.3489
Pair 11	IND1	26	6	20.015	4.0753	3.33	.5013
Pair 11	IND2	26	6	21.415	2.9942	3.57	.6822

Note. CMF = Comfort scale; FC = Functional Competence; PRI = Privacy; DIG = Dignity; MA = Meaningful Activites; REL = Relationships; AUT = Autonomy; ENJ = Enjoyment; SWB = Spiritual Well Being; SEC = Security; IND = Individuality.

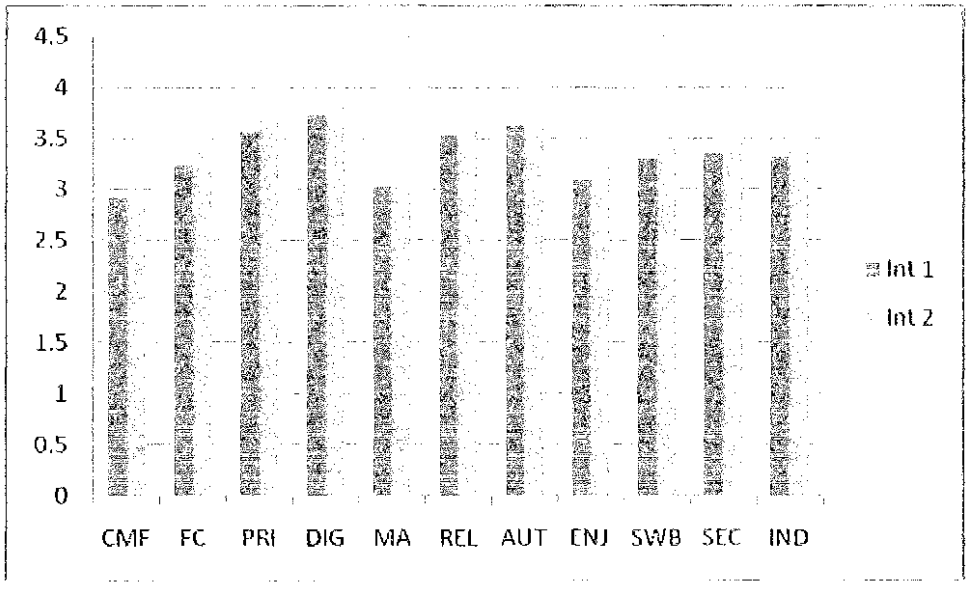


Figure 1 Comparison of Means QOL Interview 1 and 2 using normalized scores

CMF = Comfort scale; FC = Functional Competence; PRI = Privacy; DIG = Dignity; MA = Meaningful Activities; REL = Relationships; AUT = Autonomy; ENJ = Enjoyment; SWB = Spiritual Well Being; SEC = Security; IND = Individuality.

Table 3 *Paired T-test Sample Statistics for Domains (Unadjusted for the number of questions)*

Paired Samples Test

		Paired Differences					t	df	Sig. (2-tailed)
		Mean	Std. Deviation	Std. Error Mean	95% Confidence Interval of the Difference				
					Lower	Upper			
Pair 1	CMF2 - CMF1	-.125	3.489	.659	-1.477	1.227	-.190	27	.851
Pair 2	FC2 - FC1	.657	2.787	.526	-.423	1.737	1.248	27	.223
Pair 3	PRI2 - PRI1	.638	2.901	.568	-.533	1.810	1.122	25	.272
Pair 4	DIG2 - DIG1	.528	1.299	.245	.024	1.032	2.152	27	.041
Pair 5	MA2 - MA1	.250	3.301	.623	-1.030	1.530	.401	27	.692
Pair 6	REL2 - REL1	.171	2.141	.404	-.658	1.001	.424	27	.675
Pair 7	AUT2 - AUT1	.385	1.593	.301	-.232	1.003	1.281	27	.211
Pair 8	ENJ2 - ENJ1	.507	1.870	.353	-.218	1.232	1.435	27	.163
Pair 9	SWB2 - SWB1	.444	1.821	.344	-.261	1.150	1.292	27	.207
Pair 10	SEC2 - SEC1	.757	1.640	.310	.121	1.393	2.442	27	.021
Pair 11	IND2 - IND1	1.400	3.586	.703	-.048	2.848	1.991	25	.058
Pair 12	SUM2 - SUM1	-1.075	7.520	1.421	-3.990	1.840	-.756	27	.456

The summary item score consists of one question for each domain and an overall QOL question summing up each domain. For example, for the dignity domain the question is "How would you rate the quality of your life here with respect to feeling that your dignity is respected?" The summary item score, according to the author, is not to be summed for an entire score, but to be used individually to compare to each individual domain scores. The summary item score is being worked on to examine "how much each domain contributes to overall QOL" (Kane, 2003). There are no specific guidelines for using this score. Therefore, a table was created to compare individual domain scores with the summary item domain scores. The individual domain scores when compared to

the summary item score was overall much higher. For example, DIG1= 3.73, SUMDIG1=3.233, DIG2= 3.84, and SUMDIG2= 3.233. This would suggest that the summary score is not a good predictor of the overall domain score in this project. (See Table 3)

Table 4 *Comparison on Individual Domain Scores with Summary Item Score*

DOMAIN	MEAN	SUMMARY ITEM	MEAN
CMF 1	2.92	SUMCMF 1	3.067
CMF 2	2.89	SUMCMF 2	2.883
FC 1	3.24	SUMFC 1	3.100
FC 2	3.37	SUMFC 2	3.000
PRI 1	3.56	SUMPRI 1	3.067
PRI 2	3.68	SUMPRI 2	3.133
DIG 1	3.73	SUMDIG 1	3.233
DIG 2	3.84	SUMDIG 2	3.233
MA 1	3.03	SUMMA 1	3.000
MA 2	3.06	SUMMA 2	3.117
REL 1	3.53	SUMREL 1	3.267
REL 2	3.57	SUMREL 2	3.233
AUT 1	3.63	SUMAUT 1	3.000
AUT 2	3.61	SUMAUT 2	3.067
ENJ 1	3.09	SUMENJ 1	2.767
ENJ 2	3.26	SUMENJ 2	2.700
SWB 1	3.30	SUMSWB 1	3.233
SWB 2	3.41	SUMSWB 2	3.150
SEC 1	3.35	SUMSEC 1	3.467
SEC 2	3.50	SUMSEC 2	3.433
IND 1	3.33	SUMIND 1	2.867
IND 2	3.57	SUMIND 2	3.000

Note. CMF = Comfort scale; FC = Functional Competence; PRI = Privacy; DIG = Dignity; MA = Meaningful Activites; REL = Relationships; AUT = Autonomy; ENJ = Enjoyment; SWB = Spiritual Well Being; SEC = Security; IND = Individuality.

Differences between the first interview and second interview were calculated and are denoted as change variables. A *t*-test was conducted and the average scores were the same as the paired *t*-test with a significant difference ($p = <0.05$) in the domains of dignity and security. The individuality domain showed marginal significance ($p =$

0.058). There is 95% confidence that the individuality domain score change could be as large as 2.84. (See Table 4)

Table 5 *T-test of Change Variable between Interview 1 and 2*

	t	df	Sig. (2-tailed)	Mean Difference	95% Confidence Interval of the Difference	
					Lower	Upper
DIGChange	2.152	27	.041	.5286	.025	1.033
SECChange	2.442	27	.021	.7571	.121	1.393
INDChange	1.991	25	.058	1.4000	-.048	2.848

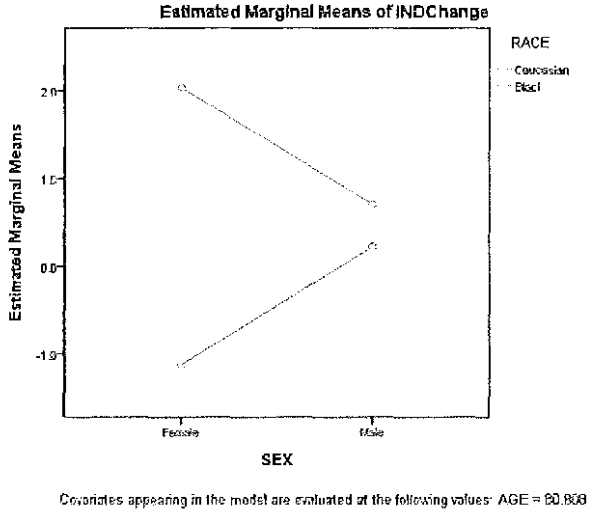
Note. DIG = Dignity; SEC = Security; IND = Individuality.

Correlations among changes in the eleven domains, as well as age, were calculated. With respect to the domains, only changes in the autonomy and privacy domains were significantly correlated ($p = 0.041$). The Pearson Correlation ($r = 0.389$) indicated only moderate correlation. It should be noted that none of the domain changes were significantly correlated with age except for ENJChange (Enjoyment) ($r = 0.395$, $p = 0.038$).

An analysis of covariance was used to see whether changes in dignity, security and individuality were influenced by gender, age or race. None of these were significant. The plot in Figure 2 shows the effects of race and sex on change in IND (individuality) controlling for age. While not statistically significant, the plot does suggest that the marginal significance of the individuality domain (paired t-test $p = 0.058$) was driven by the Female Caucasian group (24 of 29 respondents), which underwent a much larger

change from the first to second administration of the QOL than the other three groups. Note that the sample sizes for these marginal means are quite small.

Figure 2 *Estimated Marginal Means of Individuality Change Race Using Race and Sex*



Interpretation of Results

Overall, the QOL demonstrated a significant change among the participants in the areas of dignity, security, and individuality. These three areas show that the person-centered care intervention did affect the QOL of the elders in this setting. In the dignity domain the questions reflected the residents' feeling of respect from the staff that they were treated gently, their modesty was maintained, and they felt that the staff listened to them when they had something to say. In the security domain, the elders felt safe regarding the safety of their belongings and their ability to get help if they were sick and needed assistance. They felt they and other residents were treated well and were not fearful of being mistreated. In the individuality domain the residents felt that the staff was interested in them as a person, was interested in their past experiences, and knew

their preferences. They felt that as individual persons they were known as individuals and their personal wishes and interests were respected. These three domains suggest that teaching the CNAs person-centered care can positively affect the quality of life of the elders.

The QOL was overall high and increased in most domains (see Figure 1), although a significant change was not noted in many of the domains. Observing the comfort scale, questions involved how often the resident was too cold, in pain, too long in one position, or if they slept well. The comfort domain scored the lowest scores in both interviews. The functional competence domain refers to how easy it is for the resident to reach items in their room and bathroom, and do as much to take care of their things and their room as much as they want. Both of these domains reflect each resident's physical abilities and disease progression. In the area of privacy at both interviews, the residents identified that they felt they had a high level of privacy in regards to finding a place to be alone, being able to make private phone calls, and having private places to visit. The meaningful activity domain was scored the lowest of any of the domains next to the comfort domain. Very few residents felt the days were too long and most enjoyed the organized activities. Many residents reported that they would like to go outside more. This is an area for improvement. Adding activities that are conducted outside would add to the QOL of the residents. In the relationship scale, even though not all the residents felt that they had a close friend that was a resident, most of the participants identified the staff as friends. In the autonomy scale the residents scored high in this area in both interviews. They felt that they could get up and go to bed whenever they wanted, choose their own clothes, and make changes when there is something that they do not like. The

domain of autonomy suggests the facility is honoring the basic concepts of culture change in natural awakening, bed times and clothing choice. The enjoyment scale reflects the residents' enjoyment of their meals and food. The scores did not change significantly between the two interviews. In December 2009, dining hours were extended to two hours at each meal and restaurant-style dining was initiated. Made-to-order breakfast was started, and the residents got to choose a meal once each month that they want. Although the residents appear to enjoy mealtime, there is room for improvement. Customer service in the dining room can be improved to offer the residents an improved dining experience. The spiritual well-being scale reflects residents' enjoyment and participation in religious activities in the facility, feeling at peace, and that their life has meaning. This scale did not change between the two interviews. This suggests that what the residents are participating in religiously has not been influenced by the person-centered care intervention.

Confounding Factors

Factors that may have affected the outcomes of the project were the annual state survey by the Agency for Health Care Administration (AHCA) and re-survey, both occurred during this time which may have distracted the unit managers and staff. There was a new unit manager on one of the units who started just prior to this study. The other unit had a new clinical coordinator who was under training by the unit manager. Both unit managers did not encourage and champion the use of the Wants and Desires forms as much as the investigator had anticipated, which was the means to increase the CNAs knowledge of the resident and person-centered care. In a study by Robinson and Rosher (2006) it was found that if the management staff is not focused on culture change then it

is difficult to give the decision-making to the front line staff and make progress on the culture change journey.

Overall, this project showed that teaching CNAs person-centered care can positively affect the QOL of elders living in a long term care facility. The foundation of culture change, including honoring natural awakenings in our elders, when he or she wants to go to bed, having meaningful activities and fine dining experiences, was evident in the results of this project. The elders felt that their autonomy and decision making was high at both interviews, although not a significant change. In the areas of dignity and security, significant improvement was shown, and marginal significance was seen in individuality between interview one to two demonstrating, in this setting, that improved quality of life can be obtained through teaching person-centered care.

Chapter 5: Discussion

Quality of life in LTC is often secondary to quality of care. Many facilities provide excellent quality of care but do not look at the quality of life of the elders living within those walls. Alexis Carrell once said, "The quality of life is more important than life itself" (Café Philosophy, 2009). This project begins to show that quality of life can be improved by teaching the frontline staff person-centered care, which is the heart of culture change. Although not all the domains were significantly improved in the QOL interviews, several areas that could be affected by practicing and embracing person-centered care were improved. Dignity, an essential for self-esteem and feeling valued and respected was enhanced. Security, or feeling that personal possessions are safe and that one can get help if it is needed, also improved. Individuality was also affected. The residents felt that they were known and respected as persons in that the staff knew what they preferred and that the staff was interested in them as people.

Limitations

Limitations of this study included a short time frame, new managers, and the distraction of the staff. A four month time period is a very short interval to create a lasting change. It is suggested that at least a six month interval between interview one and two be used if the project is replicated. New staff, especially management staff, is often overwhelmed in a new position and championing culture change may not have been a priority. Assisting the new management staff to become supporters of the culture change journey prior to the start of the study may also have changed the outcome. Major changes are difficult to implement and maintain when the staff is distracted and focused

on other projects, like the annual survey and re-survey. Starting the project once the annual state survey was complete may have focused the staff more on the project and working on "knowing" the elders better.

Recommendations

This project was conducted over a four month period, which is a very short time to facilitate a change. Recommendations for this project are for the CNAs to continue to use the Wants and Desires form on the units to get to know new residents as they move into the units. The unit managers and clinical coordinators need to embrace the idea of culture change and become the champions on the unit. It would be beneficial to conduct the QOL interviews again in six months to see what changes have occurred in that time with their perceptions of their quality of life and compare them to the first and second interviews.

In using the QOL tool, it became apparent that two areas needed improvement: dining and activities. Meetings are recommended with the nursing and dietary staff and residents to discuss what is working with the dining times increased to two hours and the restaurant-style dining, as well as areas for improvement, including satisfaction with menus. Learning circles (Norton, 2003) will be used as a way to allow all the staff to voice their opinions in a safe manner. This technique allows a facilitator to ask a question of the 10-15 participants. Each person is allowed one to two minutes to express their feelings and opinions without cross talk, followed by a discussion.

Recommendations to improve activities are to have activity carts available on each of the units so that the CNAs can spontaneously conduct informal activities with the residents. The carts are old treatment carts that are not in use. The cost involved would

be the cost of materials to fill each cart with different activities for the residents to do. Several card tables would also need to be purchased. Drawbacks of this plan would be a place to store the cart and the card tables. In-servicing of the staff would also be needed to teach the CNAs and nurses how to use the activity materials and how to interact with the residents during each activity.

The residents also identified that they would like to go outside more often. This can be done within activities, but also by the frontline CNAs as they practice person-centered care. This is a cost-free recommendation that involves the staff identifying who likes to go outside and incorporating that into the day. Small groups can also plan to take smaller numbers of residents outside at a time. Improvements in dining and outside activities may also be incorporated during the spring and fall picnics and/or barbeque

One suggestion for activities and nursing improvement is to change some of the CNAs assignments to become QOL CNAs. These aides would be responsible for overseeing the care on one hall, for serving in the dining rooms and in coordination of activities. They would be responsible for many small group activities and great customer service in the dining room. This would not involve an increase in staffing, but instead rearrangement of the current staff responsibilities. Many of the staff provide excellent care on the units, but do not like to serve in the dining rooms and are not good at small group activities. This rearranging would allow for all of the talents of the staff to be utilized to each individual's maximum potential. While this may be a way to address the dining and activity areas for improvement, a potential downside of this would be having enough QOL CNAs to staff seven days a week. This would involve careful and meticulous planning around the clock, for both weekdays and weekend.

In a study by Robinson and Rosher (2006), the staff identified at least one of "Life's Simple Pleasures" for each resident. This can be as simple as having coffee at 6 A.M. when the resident wakes up, to ice cream cones on Tuesdays, to sitting outside for a half hour each day. This would be an inexpensive way to increase the resident's QOL by providing one thing that they really enjoy each day. This may be easily accomplished by creating a form for residents and their families to fill out. The primary CNA would then be responsible for helping make the "Simple Pleasure" happen. Potential problems would be the staff not following through with each resident's "Simple Pleasure". Ways to ensure consistent participation is have each resident's "Simple Pleasure" on the assignment sheet incorporated as part of the CNAs job assignment. This would ensure that whether the primary CNA was working or not, the "Simple Pleasure" continued.

Application to Current Practice

Person-centered care is just the beginning of truly changing the culture of the facility. The language of the facility also needs to change. For instance, the residents have chosen to rename the units in the facility. The elders live in an "apartment" (not a room) in "neighborhoods" (not a unit) within a "community" (instead of a facility). The CNAs become personal care assistants or certified personal assistants. The units will be decorated based on the theme of the neighborhood with the resident's input and approval. Changing the language also involves in-servicing the entire staff, residents and families, which is the only cost of this change. It is then up to the staff and residents to police itself and correct each other when they hear someone use the "old" language until the "new" language becomes a natural part of the culture.

The entire idea of a community is needed. Dr. Barry Barkan (2003) uses the idea of community as the basis of his Live Oak Regenerative Community. Each morning the community (residents, staff and families) gather and have a welcoming ritual and song, share news of the world, news of home (including what residents and staff have to share), a discussion of the day and a closing song. This could easily be incorporated into the current morning activity "News and Views". This recommendation is entirely free, has a huge impact in changing the culture and how the facility sees itself as a community. It would be up to the Activity staff to embrace this and make it a part of daily life at the facility.

In a study by Clarke et al. (2003) person-centered care was encouraged through telling the resident's life story using photographs of the residents and creating a scrapbook. The scrapbook would also encourage the involvement of the families to assist with the project. The QOL CNAs, primary CNAs, and nurses could all assist in making the scrapbooks over a six to eight month period. This would cost more than the other projects, as it would include the cost of the scrapbooks, scrapbook materials and the cost of copying the family pictures. This is a project to be incorporated in the future when person-centered care is a norm in the facility.

All of these ideas fit well with PHCC's strategic plan, which is to continue the culture change journey. There is still much work to do to truly transform the culture of the facility. The Quality Partners Rhode Island (2006) has created many in-services to assist a facility to transition from a medical model to person-centered care within their HATCh model. These classes will be used to further the adoption of person-centered care.

Application to Other Settings

This project may easily be used within any LTC or Assisted Living Facility. The "Quality of Life Scales for Nursing Home Residents" (Kane, 2003) has very clear instructions and can be used with alert and oriented residents. The teaching outline, PowerPoint presentation, Resident sensitivity tool and the Wants and Desires form are all easy to use and understand. A facility would need the use of a statistical program, such as Excel, to analyze the results if they want to measure for statistical significance.

Timing is also important. A six month time span might be a better time period between interview one and two. This would give the facility time to more fully embrace person-centered care. Starting this project after the annual survey has been completed for the year would be advised instead of when the surveyors are expected any day. Starting any project around the Thanksgiving/Christmas/New Year holiday is also to be avoided.

Conclusion

Person-centered care is the heart of culture change. If culture change is to be embraced by the entire staff they must move from a medical model to person-centered care. In completing this project it was shown that teaching CNAs person-centered care can improve the quality of life of alert and oriented residents living in long term care in this setting. This study suggests that dignity, security and individuality can be improved to create a better quality of life for these elders living in LTC. Resident choice about times to get up, go to bed and personal choices like what they want to wear each day are honored in this project. The beginnings of culture change, with honoring natural awakenings, choice in bedtimes and understanding the resident as a person with a rich

past and contributions still to be made within the community they live in, can be made through teaching person-centered care.

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Authors Pub Year Country	Dependent Variable	Independent Variable	Study Design	Sample Size	Sampling Method	How Data was Collected	Gender Age	Intervention Control	Outcome Measures	Major Strengths	Major Weaknesses
Elliott, A. USA Providence Mount St. Vincent - A case for sustainability			Case Study	4 floors of skilled nursing units with 56 beds/unit changed to 9 neighbor hoods with 20-23 residents in each neighbor hood	Interviews , review of facility records	41 quantitative data sources (financial, staff, operations, resident, outcomes) 36 sources of organization al data (descriptive, educational materials, human resources, communicati on, marketing, operations) 28 interviews	Staff working at and elders living at Provide nce Mount St. Vincent	Person-centered care with environment al changes (small neighborhoo ds) change in policy and procedure, flattened the hierarchy to put resident at the top with direct caregivers next	Satisfactio n surveys, occupancy rates, quality care measurem ents (restraints, weight loss, pressure ulcers), staff turnover, staff surveys. Resident and staff interviews	Shows how multiple departmen ts need to be involved in culture change. Examples of how the units were changed into "neighbor hoods" and how person-centered care was at the heart of it. Multiple measures of improvem ents, from care issues to quality of life to staff satisfactio n and turn over were measured	Overview, but few specifics of what was done educationall y to change from a medical model to person-centered care

Ragsdale, V., McDougall, G. 2008 USA The changing face of long term care: Looking at the past decade	Resident satisfaction	Green House living	Comparati ve Study	2 traditional nursing homes and 2 nursing homes converted to Green Houses	Quality Indicators satisfaction surveys	MDS was used to capture resident quality indicators. Staff outcomes including absenteeism, turnover and work related injuries. Compared "Green Houses" to 2 traditional nursing homes. Staff interviews	Elders of various case mix and their staff. Residents receiving end of life or palliative care were excluded	Green Houses compared with 2 traditional NH	Quality indicator results, satisfactio n of residents	Compared residents in long term care between "Green Houses" 140 residents from traditional nursing home moved to 4 Green houses (based on Eden alternative) and 2 traditional nursing homes. Showed small houses increased quality indicators, satisfaction of residents and staff and decreased turnover	Quality of life was not measured in this study, just satisfaction. QOL would be interesting to measure as compared to a traditional facility

Weiner, A., Barsade, S., Burrack, O. 2008 USA Culture change in the nursing home: The impact of elder, staff and family			Longitudinal Study	Time I 1287 staff, 199 NH elders, 108 family members. Time II 280 staff, 233 NH elders, 122 family members. Time III 216 Staff, 218 NH elders, 170 family members	7 culture change communities, 6 control communities	NH elders-satisfaction and perceived QOL, interviews with primary day and evening CNA on behavioral measures, chart review. Family surveys-degree that culture change values were implemented in their communities and family satisfaction with the NH Staff surveys on satisfaction, burnout, participation in decision making, collaborative decision making in the communities, perceived implementation of organizational values on the communities	Elders, staff members and elder's family members in 13 communities studied	Measured over 3 time periods changes in culture change at 13 facilities in N.Y.	Survey, QOL and behavioral measures of residents, turnover of staff, empowerment of CNA.	Measured culture change initiatives over time in 13 communities in N.Y. Showed increased QOL and satisfaction among elders, families and staff	How QOL was measured was not discussed except as a survey. Unknown if a reliable and valid QOL tool was used. The surveys used were also not discussed in detail so evaluation of the questions cannot be done

						Community coordinator, unit manager and nurse on each community questionnaire on culture change initiatives in their communities.					
Bond, G., Fiedler, F. 1999 USA A Comparison of leadership vs. renovation in changing staff values	Change in organizational culture measured on 3 survey scales	Goal setting and architectural renovation	Pre-post case study design	3 nursing units with 65 staff (nurses, CNAs, neighborhood coordinator, recreational therapy, SW, HK)	3 nursing units pre and post test with intervention	3 scales: 1) scale describing the neighborhood's culture 2) "encouragement scale" degree that staff encourages resident to be independent 3)"team relations scale"	All staff on 3 units	1unit had architectural changes to make more "home-like" 1 unit had goal setting/behavioral modeling approach, 1 no changes (control)	3 scale results on each of the 3 units. "Encouragement scale"- degree that staff encourage residents to be independent. Scale describing neighborhood's organizational culture. "Team relations" scale. Collected at baseline and 6 months	Had a control unit with no changes made to it. Measured staff responses to various scales pre and post implementation. All 3 scales had alpha of .80 or greater. Statistically significant that change in environment was more effective than behavioral /role model changes	The hypothesis of this study was not articulated. It was not until the end of the article that I found that the "control" unit was also beginning to start "neighborhoods", just not with architectural or behavioral changes

Robinson, S., Rosher, R. 2006 USA Tangling with the barriers to culture change			Longitudinal study	151 bed nursing home in Missouri	Pre and post survey	Depression in older adults (Geriatric Depression Scale and the Cornell Depression in Dementia Screen), staff satisfaction Quality of Work-life Questionnaire), family satisfaction (Family Questionnaire)	Elders, staff and families	4 phases of Eden Alternative	Family satisfaction, Depression (decreased in residents), no real difference in staff satisfaction (only 1/3 of original staff still there 2 years later)	Plan for each phase with Eden Alternative consultants and coaches that were "experts" on Eden Alternative. Identification of need for administration to "buy in" to flattening the hierarchy and giving control of decisions to the direct care givers. "Life's Little Pleasures" of resident identified. Recommendations for "Infusing Culture Change". Recommendations for "Researching Culture Change" and Barriers to Culture Change identified	Despite all the changes no real difference in staff satisfaction. This is attributed to turnover in administrative staff that were not champions of culture change. Changes were not controllable by the researcher

Grousch, K., Medvene, L., Wolcott, H. 2009 USA Person-centered caregiving instruction for geriatric nursing students	Care of LTC resident by student CNA	2 hour program on person-centered skills	Quasi-experimental	Intervention class = 8, Control class = 13	Trained coders judged whether each student interaction was person-centered	5-8 minute videotape interaction. CNAs in both groups had to assist a resident to put on his shoes and sweater, get him up using a gait belt and walk him to dinner with his walker. The resident had smeared glasses and rubbed his leg as he walked. Each CNA was videotaped and were assessed for person-centered care using PCBI, GBS and RSS scores	2 successive classes of geriatric nursing assistant - no significant difference between the groups (female age 20-51, M= 34, SD= 11.10 years	A control (1class) and intervention group (class 2 which had 2 hours of class on person-centered care with PowerPoint, "task-centered care "and video (Putting Person Before Task)	Person-Centered Behaviors Inventory (PCBI) and Global Behavior Scale (GBS) assessed the person-centered behaviors exhibited by nursing assistant students and the resident used a Resident Satisfaction Survey (RSS)	Very detailed explanation of study and intervention. The PCBI, GBS and RSS were developed by the authors, but have Cronbach alphas of .80 and above. Hypothesis was statistically supported, but no real difference in 2 classes	2 hours is a short time to try to train CNAs, especially students who do not have a background in nursing care to learn a new way to interact with a resident

Caspar, S., O'Rourke, N., Gutman, G. 2009 Canada The differential influence of culture change models on LTC staff empowerment and provision of individualized Care			Pre- and-post survey	Convenience sample of RNs, LPNs, and care aides from 54 LTC facilities in British Columbia	Staff volunteered for questionnaires	4 Questionnaires given to RN, LPN and care aides in different order of presentation	RN, M=8, F=169 Age 20-65; LPN, M= 6, F= 58, Age 20-60; CNA, M= 25, F= 298, Age 22-64	48% of facilities had implemented a culture change model (CCM)	Condition of Work Effectiveness Questionnaire (CWEQ) 4 subset (information, support, resources, opportunity) Jobs Activity Scale (JAS) Staff perception of formal power with work environments Organizational Relationship Scale (ORS) Staff perception of informal power in work environments. Individualized Care Instrument (ICI) measures care staff ability to provide individualized care	The study shows that the traditional hierarchal medical model remains evident in LTC . The care staff furthest from the resident has the most power to make decisions (RNs) To successfully initiate culture change the care staff needs to be empowered to make these decisions. Statistical analysis well done	Convenience sample, cannot generalize results, more study needs to be done on empowerment. 4 questionnaires, very lengthy, too much burden on the staff, especially CNAs who may have a lower reading/ comprehension level

Tellis-Nayak, V. 2007, USA A person-centered workplace: The foundation for person-centered caregiving in long-term care			Survey	CNA survey- 3579 responses from 156 facilities. Family survey- 6502 responses from the same 156 facilities compared to state survey results Nov. 2003 to Nov 2004	Satisfaction surveys	Survey - Staff had 18 items on 4 dimensions of quality: training, supervision, management by administrator and DON, and work environment. Family had 24 item including quality of care, quality of life and quality of service. State inspection survey results from each of the 156 facilities	CNAs and family members. Age and gender were not part of the survey		Averaged CNA and family scores for each facility for each question. Could then correlate CNA and family responses from the same facility with state survey results. "Compliance Scale" (0% - 100%) computes facility compliance to standards by multiplying deficiencies with the correspondin g scope and severity	Data showed that managers play an important role in CNA loyalty, commitment and satisfaction. This in turn results in well being of the residents. If person-centered care is to be initiated this study's findings help to identify what is important to the CNAs , which is then passed onto the residents as quality care. Statistical analysis was done on many levels including data reduction, correlational statistics, and risk analysis	No data was gathered on facility backgrounds , the settings so generalizatio n about regions and types of facilities could not be made. The state survey data was collected in the 12 months following the surveys. The staff and families that did the surveys may have changed by the time the survey was done, DON or administrator s may have changed or the facility could have been sold

Clarke, A., Hanson, E., Ross, H. 2003 USA Seeing the person behind the patient: enhancing care of older people using a biographical approach			Qualitative	8 patients and their families and 6 support workers	Support workers helped to compile life stories written by family members, care aide or pictures supplied by the family. Focus group at the beginning and end of the study	Focus groups/interviews transcribed in full ,thematically analyzed the transcripts for similarities and differences	Not discussed in the article		Focus groups interviews transcribed by researchers	This study showed that use of biographical data helped to improve person-centered care. The staff saw who the person was, not just an elderly sick person. The staff found that they had better relationships with the families because of the story telling Good qualitative approach to gathering of data	Very small sample, the authors did not discuss the themes that they found from the study and results were generalized

Rantz, M., Fleshner, M. 2004 USA Person-centered care: A model for nursing homes			Case Study	Rural nursing home in Missouri		MDS and quality indicators, interview of staff, staff levels, case mix	Staff and residents of the nursing home		Quality indicator results, nurse staffing levels, financial reports, staff interviews, satisfaction surveys of staff and residents	Many quantifiable measures were used to show improvement in quality of care after person-centered care was initiated including satisfaction & improvement of quality indicators. Forms used to "know" the resident are included (Life History, Wants and Desires)	Case study which is difficult to generalize to other nursing homes due to many individual differences in each building

Appendix B

Resident Sensitivity Exercise

Your Daily Routine:

When I have a choice I wake up at _____ am/pm.

The first thing I like to do when I get out of bed is _____.

If I could have whatever I wanted for breakfast it would be _____

_____.

When I have time to watch TV I like to watch_____.

When I have free time I like to_____.

I like to bathe (when)_____ with a shower/tub bath.

Right before bed I like to relax by _____.

I like to go to bed at _____am/pm.

Elliott, A. (2008). Providence Mount St. Vincent- A case for sustainability. The Pioneer Network Case Studies. Retrieved from www.pionernetwork.net

Appendix C

WANTS AND DESIRES FORM

NAME:	WOULD LIKE TO ACCOMPLISH	LIFE HISTORY & HABITS	DAILY ROUTINE
			Favorite Drink
IMPROVEMENTS			Preferred Foods
			CYCLE OF DAILY OF EVENTS
	PERSONAL CARE ROUTINE		AM routine
	Bath routine		PM routine
	Unique hygiene needs		ADL routine
	Needs assistance with		ROOM PREFERENCES

WANTS AND DESIRE FORM
CRESTVIEW NURSING HOME, INC.

Rantz, M., & Flesner, M. (2004). *Person centered care: A model for nursing homes.* Washington, DC: American Nurses Association.

Appendix D

Measures, Indicators, & Improvement of Quality of Life in Nursing Homes

Quality of Life Scales for Nursing Home Residents

Study Director, Rosalie A. Kane

CMS Project Officer: Mary Pratt
CMS Co-Project Officer: Karen Schoeneman

December 2003

These measures were developed and tested as part of the CMS project, *Measures, Indicators and Improvement of Quality of Life in Nursing* Homes conducted under Master Contract #500-96-0008 between CMS and the University of Minnesota.

For further information, contact Rosalie Kane at Division of Health Services Research & Policy, School of Public Health, University of Minnesota, 420 Delaware St., SE, Box 197, D-527 Mayo Building, Minneapolis, MN 55455. Phone 612.624.5171, Fax 612.624.5434, or email: kanex002@tc.umn.edu

Quality of Life Scales for Nursing Homes

Background

In 1998, the Center for Medicare and Medicaid Services (CMS) awarded the University of Minnesota School of Public Health a contract to conduct a study called *Measurement, Indicators and Improvement of the Quality of Life in Nursing Homes*. One of the main purposes of this project was to develop and test measures of quality of life (QOL) of older nursing home residents, emphasizing psychological and social aspects of QOL. The goal was to obtain information on QOL from as many nursing home residents over age 65 as possible, including those with cognitive impairment.

The measures provided here should be based on data collected from interviews with nursing home residents where residents are asked the actual questions that comprise the scales. Although it is possible to interview care personnel or family members about an individual resident to obtain proxy reports of a residents' QOL, we recommend against this strategy because our study showed that staff and family answer the questions differently from the residents for whom they were reporting.

The QOL items were administered to residents as part of a larger interview, which contained more candidate items on QOL than were eventually incorporated into scales, as well as some additional questions. The shortened scales presented here are relatively independent of each other, have acceptable levels of internal reliability and test-retest reliability, and have been shown to have good validity. The scale development was performed with a sample of 1988 residents in 40 nursing homes in 5 states, about 1300 of whom were able to complete all or most of the scales.

The properties of and results of analyses with these measures are described in technical manuscripts now in progress. Thus, information about scale reliability, test-rest reliability, and validity is not included here. Those wishing to use the tools can contact investigators at the University of Minnesota as described on the cover page of this document.

Domains of Quality of Life

The scales presented here assess 11 domains of QOL. As of today, no attempt has been made to combine them into a single score. In addition, the scales are not meant to tap the entire construct of QOL. The measures should be used in conjunction with other established measures of functional status, self-rated health and affect measures, which also tap components of QOL.

The domains for which measures were developed and the generation of items for the scale was guided by a thorough review of literature, discussion with experts, and focus groups with residents. Additionally, the study explicitly included domains of quality of life that nursing homes are expected to optimize under current federal regulations. The quality of life outcomes are defined in the box below.

Domains and Their Definitions
Physical comfort. Residents are free from pain, uncomfortable symptoms, and other physical discomforts. They perceive that their pain and discomfort are noticed and addressed by staff.
Functional competence. Within the limits of their physical and cognitive abilities, residents are as independent as they wish to be.
Privacy. Residents have bodily privacy, can keep personal information confidential, can be alone as desired, and can be with others in private.
Autonomy. Residents take initiative and make choices for their lives and care.
Dignity. Residents perceive their dignity is intact and respected. They do not feel belittled, de-valued, or humiliated.
Meaningful activity. Residents engage in discretionary behavior that results in self-affirming competence or active pleasure in the doing of or watching of an activity.
Food enjoyment. Residents enjoy meals and food.
Individuality. Residents express their preferences, pursue their past and current interests, maintain a sense of their own identity, and perceive they are known as individuals.
Relationships. Residents engage in meaningful person-to-person social interchange with other residents, with staff, and/or with family and friends who live outside the nursing home.
Safety, security & order. Residents feel secure and confident about their personal safety, are able to move about freely, believe that their possessions are secure, and believe that the staff has good intentions. They know and understand the rules, expectations, and routines of the facility.
Spiritual well-being. Residents' needs and concerns for religion, prayer, meditation, spirituality, and moral values are met.

Using the Scales

Various users will develop their own practices for applying the scales. Below are some guidelines and caveats that emerged from our fieldwork, which are based on two waves of data collection involving interviews with approximately 3500 residents in 100 nursing homes. The second wave of data collection is scheduled to be completed by December 2001.

Whom to interview. All older nursing home residents other than those who are comatose or in a vegetative state should be approached to participate. In our study, the interview on quality of life was attempted if the resident could sustain a simple conversation. Once begun, data collection was discontinued if the resident could not respond meaningfully (that is, with other than no response, don't know, or non-sequitors) to 4 of the first 6 questions asked. The intent was to include residents with a wide range of characteristics in terms of functional status, cognition, sensory impairment, and length of time since admission, and to limit pre-emptive exclusions to a few obvious situations.

Sample size for facility-level estimates. If there is an intent to use the measures to generate average QOL scores for a facility, an adequate sample of completed interviews is necessary. Our preliminary work suggests that if an alpha error is set at 5% and power is set at 80%, a random sample of 17 responding residents per facility is sufficient to calculate a reasonable facility estimate for all domains (7-17). For an alpha of 1% and

power of 90%, a sample of 25 residents was sufficient for all domains but one (the range was from 14 to 32 subjects depending on the domain). These estimates may be revised downwards based on analyses conducted in a new sample of 60 additional facilities in 5 states.

Context and confidentiality. It is important to establish a comfortable and, as much as possible, private context in which to conduct the interview, and to pace the questions so that residents can take their time to consider their responses. In our field test, interviews were conducted by study personnel, and residents were assured that their responses were confidential and would not be communicated to nursing home personnel. A test is presently underway to see whether responses would differ if interviews were conducted by nursing home staff.

Training. Interviewers completed extensive training on how to administer scales. They were taught to repeat the response categories frequently during the interview. Training emphasized how to establish good rapport without biasing the results, guessing, or abandoning the response categories. Large-print cards with the response categories were shown to those whose eyesight permitted their use. Interviewers were also taught to give the resident enough time to think about each answer, which often meant that residents made extensive comments about the topic while thinking of their answer. Interviewers were taught to recognize this process as important to collecting valid answers, but to return to the questions and the response categories, asking residents to answer taking all they had been saying into account. If necessary, the interviews were divided into more than one sitting to avoid fatiguing residents or to fit into their schedule. The entire interview ranged from 40 to 90 minutes. The quality of life scales were a shorter component of that interview, taking about ½ the time, about 20 to 45 minutes.

Question order. In the University of Minnesota QOL study, the domains were measured in the order presented below. Pre-testing suggested that the comfort scale was a good one to begin with because it is easily comprehended and not threatening. Order effects have not yet been tested.

Likert Versus Dichotomous Responses. All but 3 questions used for the scales are preferably answered in a 4 point Likert format: "often," "sometimes," "rarely," "never." If residents were unable to respond in that format after multiple attempts, the question was repeated and residents were asked whether their response would be "mostly yes" or "mostly no." Some residents use the dichotomous response only occasionally and others do so for the whole interview. Interviewers were instructed to attempt the Likert-type response option wherever possible. For residents who ordinarily could respond to Likert-type response options, three tries were made before the interviewer allowed the use of the dichotomous response option.

Developing a Score. To maximize the number of residents providing quality of life data, we blended the two modes of response: Likert-type and dichotomous. We empirically derived a formula for combining these responses, where all "mostly yes" responses were re-scaled to 3.8 and all "mostly no" responses rescaled to 1.5. A higher

score on a domain meant a better quality of life on that domain. This scoring solution is based on Wave 1 data; it may be modified after Wave 2 data are analyzed.

Missing items. To create a score for a domain at least 75% of questions must be answered with either a Likert response or a dichotomous yes-no response. When that condition was met, missing items (that is, items where the respondents refused to answer, did not know, or where no answer was present) were imputed at the average of that respondent score for all the items he or she completed for the domain.

Lead questions. The following question could be used as a lead in to the quality of life scales: *"I am going to ask you some questions about the quality of life here at (name of nursing home). We are asking these questions so that we can see how well we are providing service to our residents (or whatever the reason for the study). There are no right or wrong answers to my questions and the whole discussion concerns what life is like for you here at (name of nursing home)."*

Each set of domain items contained its own lead-in statement, which is reproduced in the scales below.

Quality of Life Scales

Comfort Scale: ***The first questions are about how comfortable you are and the help you get to make you more comfortable.***

CMF		Often	Some-Times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	How often are you too cold here?	1	2	3	4	1.5	3.8	0	0
2	How often are you so long in the same position that it hurts?	1	2	3	4	1.5	3.8	0	0
3	How often are you in physical pain?	1	2	3	4	1.5	3.8	0	0
4	How often are you bothered by noise when you are in your room?	1	2	3	4	1.5	3.8	0	0
5	How often are you bothered by noise in other parts of the nursing home, for example, in the dining room?	1	2	3	4	1.5	3.8	0	0
6	Do you get a good night's sleep here?	4	3	2	1	3.8	1.5	0	0

4 out of the 6 questions must be answered in first 6 columns to construct the scale. 2 DK/NR responses may be imputed to domain score average. Score Range: 24-6. A higher score is more positive.

Functional Competence Scale: ***The next questions are about how easy it is for you to do things for yourself as much as you want.***

FC		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Is it easy for you to get around in your room by yourself?	4	3	2	1	3.8	1.5	0	0
2	Can you easily reach the things that you need?	4	3	2	1	3.8	1.5	0	0
3	If you are anywhere in the nursing home and need a bathroom, can you get to one quickly?	4	3	2	1	3.8	1.5	0	0
4	Can you easily reach your toilet articles and things that you want to use in your bathroom?	4	3	2	1	3.8	1.5	0	0
5	Do you do as much to take care of your own things and your room as you can and want?	4	3	2	1	3.8	1.5	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: Score range 20-5. A higher score is more positive.

Privacy Scale: ***The next questions are about privacy or lack of privacy.***

PRI		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR REF
1	Can you find a place to be alone if you wish?	4	3	2	1	3.8	1.5	0	0
2	Can you make a private phone call?	4	3	2	1	3.8	1.5	0	0
3	When you have a visitor, can you find a place to visit in private?	4	3	2	1	3.8	1.5	0	0
4	Can you be together in private with another resident (other than your roommate)?	4	3	2	1	3.8	1.5	0	0
5	Do the people who work here knock and wait for a reply before entering your room?	4	3	2	1	3.8	1.5	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score range 20-5. A higher score is more positive.

Dignity Scale: ***The next questions concern respect for your dignity.***

DIG		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Do staff here treat you politely?	4	3	2	1	3.8	1.5	0	0
2	Do you feel that you are treated with respect here?	4	3	2	1	3.8	1.5	0	0
3	Do staff here handle you gently while giving you care?	4	3	2	1	3.8	1.5	0	0
4	Do staff here respect your modesty?	4	3	2	1	3.8	1.5	0	0
5	Do staff take time to listen to you when you have something to say?	4	3	2	1	3.8	1.5	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: 20-5. A higher score is more positive.

Meaningful Activity Scale: ***Now we have some questions about how you spend your time.***

MA		As much as You want?	Too Much?	Too Little?				Mostly Yes	Mostly No	DK	NR/ REF
1	Do you get outdoors:	4	1	1	Do you get outdoors as much as you want?			3.8	1.5	0	0
				Every day	Several times a week	About once a week	Less than once a week	Less than once a month		DK	NR/ REF
2	About how often do you get outdoors?			4	3.25	2.50	1.75	1		0	0
				Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
3	Do you enjoy the organized activities here at the nursing home?			4	3	2	1	3.8	1.5	0	0
4	Outside of religious activities, do you have enjoyable things to do at the nursing home during the weekend?			4	3	2	1	3.8	1.5	0	0
5	Despite your health condition, do you give help to others, such as other residents, your family, people at this nursing home, or the outside community?			4	3	2	1	3.8	1.5	0	0
6	Do the days here seem too long to you?			1	2	3	4	1.5	3.8	0	0

4 out of the 6 questions must be answered in first 6 columns to construct the scale. 2 DK/NR responses may be imputed to domain score average. Score Range: 24-6. A higher score is more positive.

Relationship Scale: ***The next questions are about your relationships here at (name of the facility).***

REL		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Is it easy to make friends at this nursing home?	4	3	2	1	3.8	1.5	0	0
		Yes			No				
2	Do you consider that <u>any</u> other resident here is your <u>close</u> friend	4			1			0	0
		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
3	In the last month, have people who worked here stopped just to have a friendly conversation with you?	4	3	2	1	3.8	1.5	0	0
4	Do you consider any staff member to be your friend?	4	3	2	1	3.8	1.5	0	0
5	Do you think that (name of the facility) tries to make this an easy and pleasant place for families and friends of residents to visit?	4	3	2	1	3.8	1.5	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale.. 1 DK/NR response may be imputed to domain score average. Score Range: 20-5. A higher score is more positive.

Autonomy Scale: ***The next questions are about the choice and control that you have.***

AUT		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Can you go to bed at the time you want?	4	3	2	1	3.8	1.5	0	0
2	Can you get up in the morning at the time you want?	4	3	2	1	3.8	1.5	0	0
3	Can you decide what clothes to wear?	4	3	2	1	3.8	1.5	0	0
4	Have you been successful in making changes in things that you do not like?	4	3	2	1	3.8	1.5	0	0

3 out of the 4 questions must be answered in the first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: 16-4 . A higher score is more positive.

Food Enjoyment Scale: ***The next three questions are about your eating experiences at (name of nursing home).***

ENJ		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Do you like the food at (name of the facility)?	4	3	2	1	3.8	1.5	0	0
2	Do you enjoy mealtimes at (name of the facility)?	4	3	2	1	3.8	1.5	0	0
3	Can you get your favorite foods at (name of the facility)?	4	3	2	1	3.8	1.5	0	0

All questions must be answered in first 6 columns to construct the scale. No imputing is allowed. Score Range: 12 to 3. A higher score is more positive.

Spiritual Well-being Scale: ***The next questions ask about your spiritual life here at (name of the nursing home).***

SWB		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Do you participate in religious activities here?	4	3	2	1	3.8	1.5	0	0
2	Do the religious activities here have personal meaning for you?	4	3	2	1	3.8	1.5	0	0
3	Do you feel your life as a whole has meaning?	4	3	2	1	3.8	1.5	0	0
4	Do you feel at peace?	4	3	2	1	3.8	1.5	0	0

3 out of the 4 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: 16 to 4. A higher score is more positive.

Security Scale. ***The next set of questions asks about how safe and secure you feel at (name of the facility).***

SEC		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Do you feel that your possessions are safe at this nursing home?	4	3	2	1	3.8	1.5	0	0
2	Do your clothes get lost or damaged in the laundry?	4	3	2	1	3.8	1.5	0	0
3	Do you feel confident that you can get help when you need it?	4	3	2	1	3.8	1.5	0	0
4	If you do not feel well, can you get a nurse or doctor quickly?	4	3	2	1	3.8	1.5	0	0
5	Do you ever feel afraid because of the way your or some other resident is treated?	1	2	3	4	1.5	3.8	0	0

4 out of the 5 questions must be answered in first 6 columns to construct the scale. 1 DK/NR response may be imputed to domain score average. Score Range: 20 to 5. Higher score is more positive.

Individuality Scale. ***The next questions are about your individual preferences for your life.***

IND		Often	Some-times	Rarely	Never	Mostly Yes	Mostly No	DK	NR/ REF
1	Taking all staff together, nurses, aides and others, does the staff know about your interests and what you like?	4	3	2	1	3.8	1.5	0	0
2	Do staff members know you as a person?	4	3	2	1	3.8	1.5	0	0
3	Are the people working here interested in your experiences and the things you have done in your life?	4	3	2	1	3.8	1.5	0	0
4	Do staff here take your preferences seriously?	4	3	2	1	3.8	1.5	0	0
5	Do residents here know you as a person?	4	3	2	1	3.8	1.5	0	0
6	Are your personal wishes and interests respected here?	4	3	2	1	3.8	1.5	0	0

4 out of the 6 questions must be answered to construct the scale. 2 DK/NR responses may be imputed to scale average. Score Range: 24 to 6. Higher score is more positive.

Summary Items: *The next twelve questions sum up what we have discussed so far. They ask for overall ratings of the quality of your life .*(Instructions to interviewer: Try to use the "excellent/poor" format. If the resident cannot use the four-item scale, go to the "yes/no" format.)

How would you rate the quality of your life here with respect to:

SUM		Excellent	Good	Fair	Poor		Yes	No	DK	NR-REF
CMF	Feeling physically comfortable?	4	3	2	1	Do you feel physically comfortable?	3.8	1.5	0	0
FC	Doing as much for yourself as you want?	4	3	2	1	Can you do as much for yourself as you want?	3.8	1.5	0	0
PRI	Having the privacy that you want?	4	3	2	1	Do you have the privacy you want?	3.8	1.5	0	0
AUT	Having choice and control in your daily life?	4	3	2	1	Do you have choices in your everyday life?	3.8	1.5	0	0
DIG	Feeling that your dignity is respected?	4	3	2	1	Is your dignity respected?	3.8	1.5	0	0
MA	Having interesting things to see and do?	4	3	2	1	Do you have interesting things to see and so?	3.8	1.5	0	0
ENJ	Enjoying your food and meals?	4	3	2	1	Do you enjoy food and meals?	3.8	1.5	0	0
IND	Following your own interests and preferences?	4	3	2	1	Are you able to follow your own interests and preferences?	3.8	1.5	0	0
REL	Having good friendships and relationships?	4	3	2	1	Do you have good friendships and relationships?	3.8	1.5	0	0
SEC	Feeling safe and secure?	4	3	2	1	Do you feel secure and safe?	3.8	1.5	0	0
SWB	Meeting your spiritual and religious needs?	4	3	2	1	Can you meet your spiritual and religious needs?	3.8	1.5	0	0
QOL	Your life as a whole?	4	3	2	1	Is your life as a whole good?	3.8	1.5	0	0

Note: These items were not summed to create a scale but used as individual criterion measures for the separate domain scales. Further work is being done to examine how much each domain contributes to overall QOL.

Investigators at the University of Minnesota are still analyzing these QOL measures. We would appreciate your sharing any comments and experiences with using these measures.

Appendix E

YAHOO! MAIL Classic

Re: Monday, November 9, 2009 2:30 PM

From: "Rosalie Kane" <kanex002@umn.edu>
To: "hatchecker" <hatchecker@bellsouth.net>

Dear Ms. Jones:

Our scales are in the public domain and you are welcome to use them. We also have a tool we have widely used to measure CNA perspectives on knowing the resident. Bascially it has 4 items and is measured at the level of the specific resident: the items tap perceived knowledge about the resident's interests and preferences; perceived knowledge about the resident's family--who is in it, who is important to them; perceived knowledge about the resident's life story--what he or she has done in his/her life, where he or she has lived; and finally perceived knowledge about his/her health condition. The stem is: How well do you think you know Mrs X in terms of . . . .

you can go to my web site http://www.hpm.umn.edu/ltcresourcecenter/ and then click research areas, and further click quality of life (or here--I did it for you) http://www.hpm.umn.edu/ltcresourcecenter/research/quality_of_life_nh.htm and you will find a great deal opf material about these tools, how to use them, score them, and so on. Feel free to contact me if you need any further help. Good luck to you.

Rosalie Kane

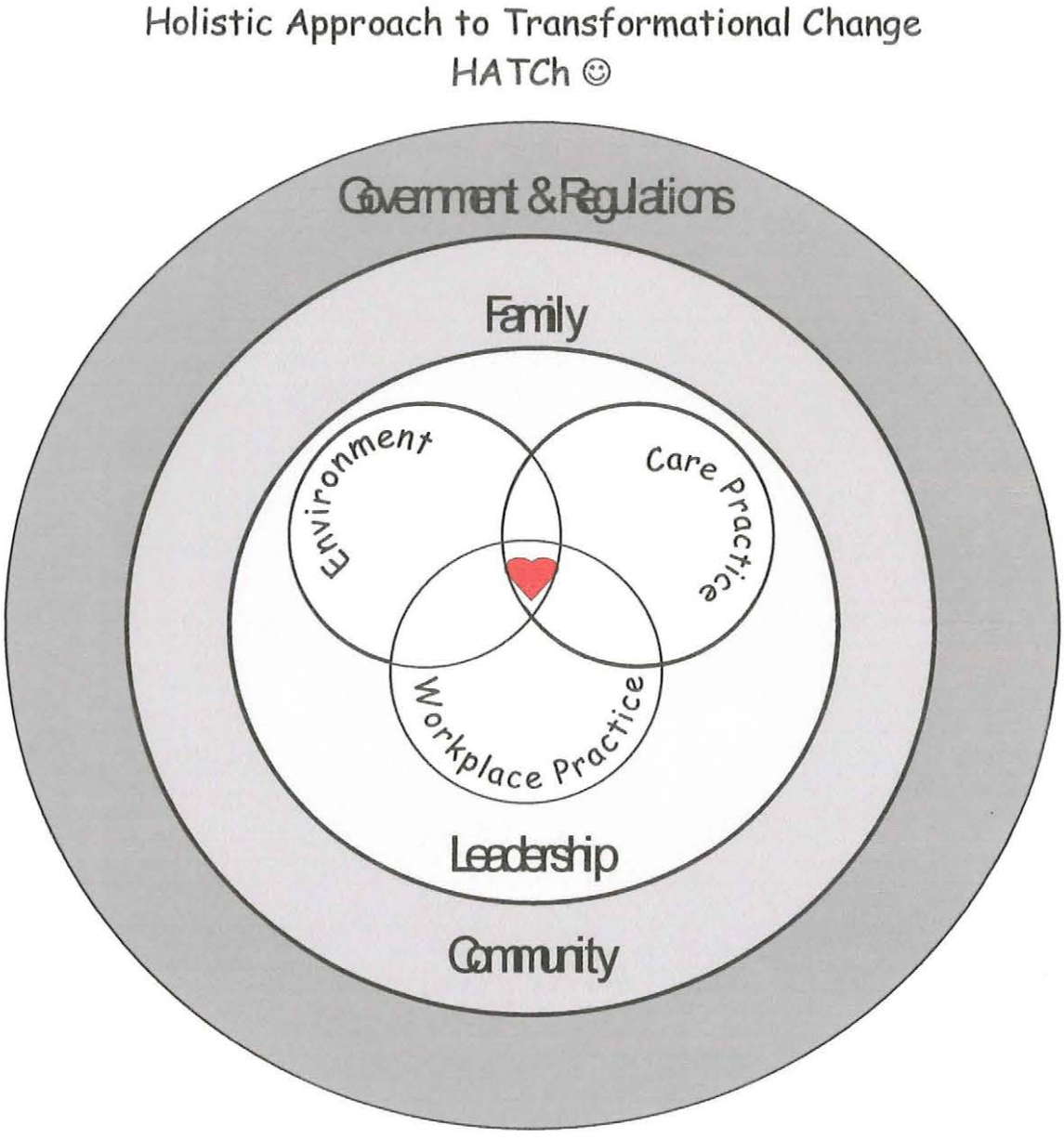
At 06:12 PM 11/8/2009, you wrote:

> Dr. Kane,
> I am a Doctor of Nursing Practice (DNP) student at the University of North Florida. I am doing my doctoral project on Quality of Life in alert and oriented elders living in a LTC facilty before and after a culture change intervention. I plan to do an inservice of person-centered care and "knowing" the resident.
> Dr. Annette Kelly shared your "Quality of Life Scales for Nursing Home Residents" with me as a tool she has used in her research here in Florida. I wanted to contact you to see if I need persmission to use your tool in my project? I find the tool captures all the areas of life in LTC much better than other tools I have reviewed.
>
> Thank you!
>
> Carol Jones, MSN, RN

Rosalie A. Kane, PhD
Division of Health Policy & Management
School of Public Health
University of Minnesota
D-527 Mayo Building, MMC 197
420 Delaware St, S.E.
Minneapolis, MN 55455
Phone: 612-624-5171, Fax: 612-624-5434
Long-term Care Resource Center Website: http://www.hpm.umn.edu/ltcresourcecenter/

We invite you to check out our new web site comparing State Nursing Home Regulations, at:

Appendix F



Quality Partners of Rhode Island. (2006). Holistic Approach to Transformational Change (HATCh). Retrieved from www.riqualitypartners.org

Appendix G

Person-Centered Care Teaching Plan I

Topic: Person-centered Care

Purpose: To contrast task-centered medical model care with person-centered care

Objective:

1. The learners will identify how they organize their day around tasks.
2. The learners will identify their own daily preferences and contrast that with living in an institution.
3. The learner will be able to verbalize three attributes of a medical model.
4. The learner will be able to verbalize three attributes of a person-centered care model.

Target Audience: The 100 Certified Nursing Assistants (C.N.A.) working at Palatka Health Care Center

Length: One hour

Materials:

1. Butterfly buttons "We Transform Care"
2. PowerPoint presentation on "Person-centered Care"
3. "Resident Sensitivity Exercise"

Activity:

1. Discussion of CNAs daily routine to identify tasks.
2. Completion of "Resident Sensitivity Exercise" with a discussion of what it would be like to live in an institution.
3. Presentation of PowerPoint slide show on "Person-centered Care".

Follow up: Ask for any questions, clarifications or additional information needed.

Person-Centered Care Teaching Plan II

Topic: Person-centered Care

Purpose: To follow up on the 1st Person-Centered Care In-service contrasting task-centered medical model care with person-centered care. The CNAs will learn how to use the "Wants and Desires" form.

Objective:

5. The learner will review and verbalize three attributes of a medical model.
6. The learner will review and verbalize three attributes of a person-centered care model.
7. The learner will be able to complete at least one section of the resident "Wants and Desires" form.

Target Audience: The 100 Certified Nursing Assistants (C.N.A.) working at Palatka Health Care Center

Length: One hour

Materials:

4. Small butterfly-shaped spiral note pad and pen.
5. "Wants and Desires" form

Activity:

1. Review of "Person-centered Care".
2. Explanation of "Wants and Desires" form. CNAs will complete at least one area on the form while at the in-service.
3. Review and discussion of how C.N.A.'s completed Wants and Desires Form
4. Recap of major points of Person-centered care with discussion of how this will change how the C.N.A. organizes their day.

Follow up: Ask for any questions, clarifications or additional information needed.

Vita

Carol S. Jones was born in Toledo, Ohio in 1959 and raised in Sylvania, Ohio. She received a diploma in nursing from the Toledo Hospital School of Nursing in 1981. She attended the University of North Florida RN to BSN program and received her Bachelor of Science degree in Nursing in 2001. Dr. Jones was awarded a Master of Nursing degree in Nursing from the University of Phoenix in 2003.

Dr. Jones has practiced nursing for the past 29 years. Her nursing career includes medical surgical nursing, emergency nursing, psychiatric and geriatric nursing. She has focused her career in geriatric nursing in a variety of administrative positions, including staff development, assistant director of nursing and risk management, in long term care since 1995. She has worked as adjunct factuly at the University of North Florida for the past 6 years teaching in the undergraduate program as a clinical instructor. She is currently is completing a Doctor of Nursing Practice at the University of North Florida.

Dr. Jones is currently awaiting the publication of a manuscript entitled "Person-centered Care: The Heart of Culture Change" in the Journal of Gerontological Nursing.